

Psychosocial Effects of Living with an Increased Risk of Breast Cancer

Sally L. R. Appleton



A Thesis Submitted for the Degree of Doctor of Philosophy

The University of Edinburgh

2003



Declaration

- This thesis has been composed by myself.
- The work contained in this thesis is my own and where others have contributed this is clearly indicated.
- The work contained in this thesis has not been submitted for any other degree or professional qualification.

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Abstract

Little is currently known about the long-term psychosocial effects of genetic risk counselling for breast cancer. This thesis presents a series of three studies to investigate the psychosocial effects of living with an increased risk of breast cancer. The participants were women who had attended genetic risk counselling at least two years previously, had subsequently been receiving regular clinical surveillance, but were not eligible for genetic testing or prophylactic surgery. A qualitative study was initially conducted to explore the long-term consequences of living with an increased risk of breast cancer in terms of: the effect on everyday life, coping strategies and needs for information and support. Twenty-five women took part in one of seven telephone focus groups and subsequently completed a feedback questionnaire. Qualitative analysis revealed six key issues, which provided a basis for further research: (1) psychological adaptation, (2) behavioural adaptation, (3) family issues, (4) clinical surveillance, (5) provision of information and (6) peer support. A cross-sectional survey of 249 women was then conducted to generate quantitative data to test and expand on the findings from the telephone focus group study. The survey was designed to assess: the prevalence of general psychological morbidity; breast cancer-specific distress; needs and preferences for information about familial risk of breast cancer and the impact of a number of factors on distress. Levels of general psychological and breast cancer-specific distress in this study were comparable to those reported in the literature. Perceived likelihood of developing breast cancer, coping style and satisfaction with social supports were predictive of distress. A widespread need was identified for up-to-date information related to familial risk of breast cancer with an overall preference for written information. A psycho-educational intervention to meet the needs of these women was developed and evaluated. It consisted of written information about scientific and psychosocial topics related to familial risk of breast cancer. Participants in this study ($n = 151$) were randomised to receive the information pack containing both scientific and psychosocial topics or the scientific topics only or no information (control group). Cancer worry and objective knowledge of scientific issues related to familial risk of breast cancer were evaluated by postal questionnaire at two time-points, four weeks apart. The results supported the hypotheses in that: the pack containing both scientific and psychosocial topics of information significantly reduced cancer worry and both versions of the information pack significantly improved knowledge relative to the control group. The implications of the results of these studies are discussed in relation to their methodological limitations, theoretical models of psychological distress, clinical services and future research.

(This thesis contains approximately 80,000 words excluding appendices)

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Dedication

In memory of all my grandparents, especially Granny Leah, who always urged me to study hard.

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Chapter 1: Review of the Literature on Familial Breast Cancer

There is a large amount of scientific literature on various aspects of familial breast cancer. The topics covered in this review were selected on the basis of being particularly relevant to describing our current understanding of the experience of living with an increased risk of breast cancer both from medical and psychological perspectives. This chapter will: provide a review of breast cancer including its aetiology, symptoms, screening, diagnosis, treatment and risk factors; discuss familial breast cancer including risk assessment and management; review and critique research on the psychosocial impact of genetic risk counselling for breast cancer and give a rationale for the current work.

The literature searches were conducted using an Endnote database (held by the Cancer Research UK Psychosocial Research Group in Edinburgh) of over 1,000 references about familial breast cancer (from 1946-2002) and the Web of Science social science/science citation indices (1981-2002). A review of psychosocial interventions in women with a family history of breast cancer is provided at the beginning of Chapter 6. Discussion of the psychological theoretical models relevant to living with an increased risk of breast cancer is included in Chapter 7.

1.1 Background to breast cancer

1.1.1 Introduction

Breast cancer is the commonest form of cancer in women both worldwide and in the U.K. One million women worldwide are newly diagnosed with breast cancer every year (McPherson et al., 2000) with over 38,000 of those being in the U.K (Cancer Research UK, 2002). One in nine women (11%) in the U.K will develop breast cancer during their lifetime. Of the people diagnosed with breast cancer in the U.K every year, the majority are post-menopausal women, about 7,000 are women under the age of 50 and approximately 200 are men (Cancer Research UK, 2002). Breast cancer accounts for more deaths in women in the U.K aged 40-50 than any other single cause. In excess of 14,000 women in the U.K die from breast cancer each year (McPherson et al., 2000).

1.1.2 Aetiology

Breast cancer is a malignant tumour in the cells of the breast. A number of factors are involved in the development of all forms of cancer, including breast cancer. These can be broadly classified into two groups: hereditary or environmental factors. Most cases of breast cancer are sporadic. This means that they occur by chance due to as yet unproven environmental factors.

However, all cancers are “genetic” in the sense that they are caused by genetic mutations arising in a single cell (Emery et al., 2000). Usually cells with mutations, which can occur by chance during cell division, are destroyed before they result in cancer. However, if these cells do not die, several different genetic mutations can accumulate in a cell, which transforms it into a cancer cell. The fact that this process can take a considerable amount of time means that many forms of cancer tend to manifest in older individuals. A cancerous tumour is formed by the cancer cells continually reproducing. They can then invade and destroy neighbouring tissue and even metastasise to areas further away in the body using the blood stream or lymphatic system.

1.1.3 Symptoms

There are number of symptoms that may indicate breast cancer. These include a lump in or thickening of the breast, nipple or armpit, a change in the size or shape of the breast, an inverted nipple, dimpling of the skin, a rash, blood-stained discharge and breast pain (Cancer Research UK, 2002). However, many of these symptoms also indicate benign breast lumps. About 90% of breast lumps are found to be benign on further examination and are usually cysts (fluid-filled sacs) or fibroadenomas (fibrous glandular tissue) (Cancer Research UK, 2002).

The type and number of symptoms experienced can vary greatly between individuals and depends on the stage of the breast cancer.

1.1.4 Screening and diagnosis

Breast cancer can be detected through various forms of screening such as mammography, ultrasound, clinical breast examination (CBE) and breast self-examination (BSE). Over 90% of all breast lumps, whether benign or malignant, are found through breast self-examination (Cancer Research UK, 2002).

Breast cancer can be diagnosed by several different types of biopsy which remove a sample of cells (i.e. needle aspiration) or tissue (i.e. needle biopsy) from the lump or the whole lump itself (i.e. surgical biopsy).

The TNM (tumour, nodes, metastases) system is used internationally to classify breast cancer into four stages (Cancer Research UK, 2002). The first three stages are known as primary breast cancer which has not spread to other parts of the body, apart from the lymph nodes in the armpit. Stage four is known as secondary breast cancer where the cancer has metastasised to other areas in the body. The grade of breast cancer (extent to which the cells are different from normal cells) can be classified as low, medium and high depending on how fast the cancer cells are growing.

1.1.5 Treatment

There are a number of different treatments for breast cancer: local treatments that target the breast (e.g. surgery, radiotherapy) and systemic treatments that target cancer cells anywhere in the body (e.g. chemotherapy, hormone therapy). The most appropriate treatment for an individual patient is influenced by a number of factors such as their age, the stage and grade of breast cancer, the size of the tumour and their overall health. Many of the treatments have both short-term (e.g. nausea, tiredness, hair loss) and long-term side-effects (e.g. lymphoedema, early menopause, infertility), which can have a negative impact on an individual's quality of life.

The success of treating breast cancer and the subsequent prognosis depends on the stage of the cancer at diagnosis. For example, 85% of women diagnosed with localised breast cancer between 1985-1989 in the U.K lived for a minimum of five further years compared to only 21% of women diagnosed with metastatic breast cancer (Cancer Research UK, 2002).

1.1.6 Risk factors

There are a number of factors that have been shown to put an individual at risk of developing breast cancer: increasing age, geographical location (i.e. women in developed countries are at higher risk), reproductive factors (i.e. early menarche, late menopause, no pregnancies, late age at first pregnancy), having a family history of breast cancer, personal history of benign breast disease, exposure to radiation, obesity (in postmenopausal women), taking the oral contraceptive pill (and for 10 years following cessation) and hormone replacement therapy (and for 1-4 years

following cessation) (McPherson et al., 2000). In addition to age (McPherson et al., 2000), having a family history of breast cancer is “one of the strongest known risk factors” for the disease (Emery et al., 2000). Women who have a first-degree relative affected by breast cancer are two to three times more likely to develop breast cancer in their lifetime than women of the same age, place of birth and marital status but without any family history of the disease (Slattery and Kerber, 1993).

Smoking (Dixon & Steel, 2001) and dietary factors such as high fat intake and high alcohol consumption are also probable risk factors, but further research is needed to confirm their relationship to breast cancer (McPherson et al., 2000).

In terms of reducing the risk of breast cancer, ongoing research is investigating potential protective factors such as hormonal drugs in women at increased risk of breast cancer (e.g. Tamoxifen, Raloxifene), lifestyle factors (e.g. diet, exercise) (McPherson et al., 2000) and breast-feeding in the general population (Cancer Research UK, 2002).

1.1.7 Summary

Breast cancer is a common, yet potentially life-threatening disease. The causes and prevention of breast cancer are not yet fully understood. As there is currently no cure, good prognosis depends on early detection through a variety of screening measures. Of the number of factors that have been shown to increase an individual's risk of breast cancer, having a family history of the disease is one of the most important.

1.2 Background to familial breast cancer

1.2.1 Introduction

Of the women who are diagnosed with breast cancer, about 10% report having a family history of the disease (Narod, 2002).

A family history of cancer is the principal clinical indicator of an inherited susceptibility to the disease. Research has suggested that inherited susceptibility to breast cancer accounts for 4-10% of all cases of breast cancer (Arver et al., 2000). Although multiple cases of cancer can occur by chance in some families, as the disease is so widespread, it is likely that a family history indicates some form of inherited susceptibility (Ponder, 2001). This may range from an almost definite

indication of inherited susceptibility such as in the rare hereditary cancer syndromes (e.g. Li-Fraumeni syndrome) to possible inherited susceptibility in familial clusters of cancer (Ponder, 2001). In contrast, some individuals may have inherited a weak predisposition to cancer without obvious familial clustering of the disease (e.g. they may only have one relative with cancer) (Ponder, 2001).

1.2.2 Breast cancer susceptibility genes

In recent years, there have been major advances in our understanding of inherited susceptibility to breast cancer. To date, a number of breast cancer susceptibility genes have been identified. Of these genes BRCA1 (Miki et al., 1994) and BRCA2 (Wooster et al., 1995) “are the most important ‘high risk’ genes” as mutations in these genes account for most familial clusters of breast and ovarian cancer (Antoniou et al., 2002).

BRCA1 and BRCA2 play a role in the suppression of tumours (Rosenthal & Puck, 1999) and are located on chromosome 17q (Miki et al., 1994) and chromosome 13q respectively (Wooster et al., 1995). Both BRCA1 and BRCA2 are large genes and numerous different mutations have been identified (Tonin et al., 1996). Some of these mutations occur with unusual regularity across a particular population (e.g. Ashkenazi Jews) whilst others are unique to a single family (Tonin et al., 1996). These mutations include deletions or insertions of a component of Deoxyribonucleic Acid (DNA) (Tonin et al., 1996). In inherited forms of cancer, unlike sporadic cancers, the genetic mutations are found in all cells (Emery et al., 2000) and therefore can be passed down to future generations. Each child of an individual carrying a genetic mutation has a 50% chance of inheriting that specific mutation and it can be inherited from either their mother or their father.

1.2.3 Penetrance

The probability of being diagnosed with breast cancer in an individual carrying a mutation in one of the breast cancer susceptibility genes differs between families and populations (Narod, 2002). This variation in penetrance could be due to genetic factors (e.g. multiple mutations in a single cell or the influence of a modifying gene) and lifestyle factors that can alter hormone levels (e.g. pregnancy, oophorectomy and oral contraceptives) (Narod, 2002).

Therefore, different studies have produced different estimates for the penetrance of BRCA1 and BRCA2. For example, Ford et al. (1994) examined 33

families with at least four members affected by breast or ovarian cancer before the age of 60. They estimated that female BRCA1 mutation carriers had a 73% chance of developing breast cancer by age 50, 87% by age 70, a 29% chance of developing ovarian cancer by age 50 and 44% by age 70. They also found that male BRCA1 mutation carriers were also at increased risk of developing colon and prostate cancer. Ford et al. (1998) have estimated that female BRCA2 mutation carriers have a 28% chance of developing breast cancer by age 50, 84% by age 70 and 0.4% of developing ovarian cancer by age 50 and 27% by age 70.

BRCA1 and BRCA2 mutations are related to the early onset of breast cancer (Ford et al., 1995). It has been estimated that 5.3% of all cases of breast cancer and 5.7% cases of ovarian cancer diagnosed under 40 years old are due to mutations in BRCA1 (Ford et al., 1995). Over one third of women who develop breast cancer aged under 29 are carriers of a mutation in BRCA1 or BRCA2 (Rosenthal & Puck, 1999). Early onset is due to the fact that if a genetic mutation in a breast cancer susceptibility gene has been inherited, it will not take as long for other genetic mutations to accumulate in a cell transforming it into a cancer cell. Research has also shown that carriers of a BRCA1 mutation who have already been diagnosed with breast or ovarian cancer are at increased risk of developing another breast or ovarian cancer (Ford et al., 1994).

In a study of 237 families worldwide where at least four members had breast cancer, BRCA1 was estimated to be associated with breast cancer in over half of the families, BRCA2 in about one third and the remaining 16% was not accounted for by either gene (Ford et al., 1998). In families with at least one male member with breast cancer, 77% of familial clusters of the disease were thought to be caused by BRCA2 mutations and 19% as a result of BRCA1 mutations (Ford et al., 1998). Research suggests that although mutations in BRCA1 cause an increased risk of breast cancer in males, it is lower than that caused by BRCA2 mutations (Ford et al., 1998) where male carriers have been estimated to have a 6.92% chance of developing breast cancer by age 80 (Thompson & Easton, 2001).

Other breast cancer susceptibility genes have been identified including p53 (Malkin et al., 1990), PTEN (Nelen et al., 1996) and most recently CHEK2 (The CHEK2-Breast Cancer Consortium, 2002). CHEK2 mutations have been shown to double the risk of breast cancer in women and increase it tenfold in men. However, research suggests that other genes that confer susceptibility to breast cancer and that account for a substantial proportion of familial breast cancer, have yet to be discovered (Ford et al., 1998).

1.2.4 Summary

There is a substantial amount of uncertainty for an individual with a family history of breast cancer. Although having a family history of breast cancer is likely to signify some form of inherited susceptibility to the disease, the exact increase in risk for an individual may not be clear. Of the few breast cancer susceptibility genes that have been identified, penetrance is limited and can vary between families and populations. Therefore, even if a specific mutation in one of these genes has been identified in an individual, their risk of breast cancer and that of their siblings or offspring is not definitive.

1.3 Assessment of familial breast cancer risk

1.3.1 Models for estimating breast cancer risk

A number of models, used both clinically and for research purposes, have been developed for predicting an individual's risk of developing breast cancer. These models use information about an individual's family history of breast and ovarian cancer and some models also include additional risk factors (Emery et al., 2000).

The Gail model (Gail et al., 1989) calculates the likelihood of an individual developing breast cancer based on several factors including their current age, age at menarche and first live birth, the number of first-degree relatives with breast cancer and number of previous breast biopsies. This model uses data collected from a subset of nearly 300,000 women participating in a case-control study of breast cancer screening (Baker, 1982).

The Claus model (Claus et al., 1994) was derived from a case-control study of 4730 breast cancer patients aged 20-54 years and their relatives (Claus et al., 1991). It is a genetic model that uses data on the number of first-degree relatives with breast cancer and the age at which they were diagnosed to estimate the probability of an individual carrying a mutation in a breast cancer susceptibility gene.

However, each model can produce distinctly different estimates of breast cancer risk (Emery et al., 2000). For example, McTiernan et al. (2001) found that the Gail model estimated breast cancer risks to be higher than those produced by the Claus model for the majority of their participants with a family history of breast cancer. There is also uncertainty regarding the validity of these models in wider populations and their accuracy has not yet been confirmed (Emery et al., 2000).

Despite these limitations, it is considered that the models still offer a useful way of estimating breast cancer risk (Eccles et al., 2000).

1.3.2 Breast cancer genetic risk counselling

In Scotland, guidelines have recently been produced for the assessment and management of women with a family history of breast cancer (Scottish Executive, 2001). Women with a family history of breast cancer are usually referred to a regional genetics department by their General Practitioner (GP). Their family history of cancer is evaluated by a genetic nurse/associate and is confirmed by checking clinical records and a corresponding pedigree is produced. They are then classified as low, medium or high risk according to specific criteria (Table 1). Low risk has been defined as less than double the general population lifetime risk (of 9%), medium risk is two to three times the population risk and high risk is more than three times the population risk (Eccles et al., 2000).

Table 1: Summary of referral guidelines to breast cancer genetics services in Scotland (Scottish Executive, 2001)

Level of Breast Cancer Risk	Criteria for Referral
<i>Low</i>	<ul style="list-style-type: none"> • Anyone not fulfilling medium or high risk criteria
<i>Medium</i>	<ul style="list-style-type: none"> • One 1st degree relative with bilateral breast cancer
	<ul style="list-style-type: none"> • One 1st degree relative with breast cancer diagnosed under 40 years or male at any age
	<ul style="list-style-type: none"> • Two 1st or 1st and 2nd degree relatives with breast cancer diagnosed under 60 years or ovarian cancer at any age on the same side of the family
	<ul style="list-style-type: none"> • Three 1st or 2nd degree relatives with breast or ovarian cancer on the same side of the family (at least one first degree relative unless history via father)
<i>High</i>	<ul style="list-style-type: none"> • An individual with a mutation in BRCA1, BRCA2 or other predisposing gene
	<ul style="list-style-type: none"> • Untested 1st degree relatives of carriers of mutations in a predisposing gene
	<ul style="list-style-type: none"> • 1st degree relatives of an individual with breast cancer (or 2nd degree via intervening male relative) in a family with four or more relatives affected with either breast or ovarian cancer or male breast cancer in three generations
	<ul style="list-style-type: none"> • One 1st degree relative (or 2nd degree via intervening male relative) with breast and ovarian cancer

Those women deemed to be at low risk are sent a letter of reassurance, which contains advice on maintaining a healthy lifestyle and breast awareness and advises them to join the National Breast Screening Programme from age 50-64. They are returned to the care of their GP, who is also notified of their risk status. Women estimated to be at moderate or high risk will receive genetic risk counselling by a genetic counsellor or qualified geneticist.

The key aspects of assessing breast cancer risk are to gain and interpret an accurate and thorough family history of cancer (Hoskins et al., 1995). Breast cancer genetic risk counselling aims to provide an individual with the necessary information for them to accurately understand both their short-term and lifetime risk of developing breast cancer (Goodwin, 2000). Accurate risk perceptions are vital in making informed choices about risk management options (Goodwin, 2000).

The procedure of assessing the risk of breast cancer in women with a family history of the disease varies slightly between and within countries. Likewise, the format in which risk estimates are given to individuals can vary (e.g. percentages, risk categories, odds ratios, lifetime risk, age-specific risk). It has been suggested that the use of several of these formats within the consultation may assist risk comprehension (Hopwood, 1997). As a woman's risk of breast cancer can change over time, for example in response to a change in family history, their risk needs to be assessed periodically to maintain an accurate estimate.

Breast cancer genetic risk counselling usually consists of discussing a number of issues: the inheritance of a mutation in a breast cancer susceptibility gene, the assessment of risk, options for risk management and genetic testing, psychosocial issues such as psychological distress and family communication (Goodwin, 2000). Guidelines for breast cancer genetic risk counselling have been developed. For example, Hoskins et al. (1995) recommend that it should include the following components: “(1) assess a woman's preconceived ideas about cancer aetiology, (2) discuss her risk perception, (3) construct a detailed pedigree, (4) assess lifetime risk of developing breast cancer based on empiric risk tables or based on the chance of inheriting an autosomal dominant predisposition gene, (5) help guide families towards appropriate surveillance, (6) identify families eligible for genetic testing and refer to a specialised cancer genetics centre offering testing as indicated, and (7) institute referrals for individuals who could benefit from psychological counselling”.

1.3.3 Summary

The process of assessing breast cancer risk through genetic risk counselling varies both between and within countries. The risk provided is influenced by the particular model used in its calculation and it can be represented in various formats. However risk is assessed, the estimates given to individuals encompass a substantial degree of uncertainty.

1.4 Management of familial breast cancer

1.4.1 Screening for breast cancer

Since it is currently not possible to prevent the development of breast cancer, screening aims to reduce breast cancer mortality by detecting disease at an early stage when treatment is more effective. Although breast cancer screening is widely recommended for women at increased risk of breast cancer, its efficacy remains controversial in women younger than age 50 (when breast tissue is generally more dense).

A number of forms of screening are currently available for detecting breast cancer. These are the traditional methods of mammography, clinical breast examination (CBE) and breast self-examination (BSE) or “breast awareness” and the relatively new methods of ultrasound and magnetic resonance imaging (MRI). To date, a limited number of studies have assessed the value of these different forms of screening in young women with a family history of breast cancer.

Kollias et al. (1998) found that annual clinical breast-examination and mammography every two years in 1371 British women with a family history of breast cancer aged under 50 was just as effective at detecting breast cancer as the U.K National Breast Cancer Screening Programme in women aged 50 or over. In the women with a family history who had been screened on a regular basis, a greater proportion (41%) of the cancers detected over the eight-year study period had a good prognosis compared to the proportion (30%) in women with a family history of breast cancer who had not received regular screening. Similar results were obtained in a five-year study of 1259 British women with a family history of breast cancer aged under 50 (Lalloo et al., 1998).

A European study of women at increased risk of breast cancer showed that 75% of the 161 breast cancers diagnosed were detected through routine

mammography and clinical breast-examination (Møller et al., 1999). The remaining quarter of breast cancers were detected through breast self-examination. As 60% of these breast cancers were caught at an early stage, the results could be seen to support the value of breast self-examination in this group of women (Møller et al., 1999). In contrast, other studies have not found that breast self-examination improves the early detection of breast cancer in women with a family history of the disease (Tilanus-Linthorst et al., 2000). Indeed, recent recommendations have actually advised against the promotion of breast self-examination in women in the general population under 40 years (Baxter et al., 2001). This is due the lack of evidence for the effectiveness of breast self-examination together with evidence suggesting possible psychological distress and an increased risk of benign breast biopsy (Baxter et al., 2001).

Macmillan et al. (2000) reports on the results of a national audit of 22 breast units providing breast cancer screening to a total of 8783 British women with a family history of the disease. Although the protocols for the frequency and type of screening varied between units, all units offered mammography, 20 offered clinical breast-examination and one offered ultrasound. The results showed that the rate of detecting breast cancer in women with an increased risk of breast cancer under the age of 50 was similar to the rate found in the U.K National Breast Screening Programme of women aged 50-64. However, the individual effectiveness of the different methods of screening in this study was not evaluated.

Tilanus-Linthorst et al. (2000) investigated the effectiveness of detecting breast cancer in women with a family history of breast cancer receiving clinical surveillance compared to symptomatic women with a family history of the disease. For four years, 294 women in the Netherlands aged 22-75 at moderate risk of breast cancer received an annual clinical breast-examination and mammography and 384 women aged 20-74 at high risk received a clinical breast-examination every six months and an annual mammography. One hundred and nine of the women at high risk also received breast MRI. Clinical surveillance was shown to detect significantly more breast cancers when they were at an early stage than in the symptomatic women and was shown to be just as effective in women under 50 years as in women aged over 50. The results suggest that a reduction in breast cancer mortality in women aged under 50 would be equivalent to that achieved in the Dutch National Breast Screening Programme. The study provides evidence for the effectiveness of clinical breast-examination in pre-menopausal women with a family history of breast cancer. It also suggests that MRI is effective in detecting breast cancers in women with a family history of the disease which are not identified by clinical breast-

examination or mammography. These findings have been supported by more recent research in 196 Canadian women aged 26-59 at high risk of developing breast cancer (Warner et al., 2001).

Although the results of these studies are encouraging in terms of the efficacy of breast cancer screening in women with a family history of breast cancer under the age of 50, further long-term multicentre research is warranted to confirm the value of clinical surveillance in this population.

1.4.2 Current recommendations for the management of women at increased risk of breast cancer

Recommendations for the management of breast cancer risk depend on the woman's age and family history and also differ to some extent between and within countries. The Scottish Executive (2001) advises that women who are estimated to be at medium risk of developing breast cancer should begin breast cancer screening when they are five years younger than the youngest age at which any relative was diagnosed with breast cancer, but at no younger than 35 years or older than 40 years. For medium risk women, mammography (two-view) is recommended to be carried out every two years from age 35, yearly from age 40 and every three years from age 50-64 as part of the National Breast Screening Programme. Clinical breast-examination for this group should be carried out yearly from age 35-64.

Women who are estimated to be at high risk of developing breast cancer should begin breast cancer screening when they are five years younger than the youngest age at which a relative was diagnosed with breast cancer (not younger than 25 years or older than 35 years). Mammography (two-view) is recommended to be carried out every two years from age 25, yearly from age 40, every 18 months from age 50 as part of the National Breast Screening Programme and every three years from age 65. From age 25, clinical breast-examination should be performed every year until age 64. In addition, women estimated to be at high risk of breast cancer should begin ovarian cancer screening at age 35 or five years younger than the youngest case of breast or ovarian cancer in their family.

1.4.3 Genetic testing

Access to genetic testing for mutations in breast cancer susceptibility genes varies both between and within countries. Eccles et al. (2000) describe the current

situation in the U.K, where genetic testing for breast cancer susceptibility has only recently been introduced.

Predictive genetic testing is not offered to all unaffected women with a family history of breast cancer. Only a minority of unaffected women at high risk of breast cancer are usually eligible. These women are from the few families where a specific mutation in BRCA1 or BRCA2 has already been found in the DNA of an individual with breast cancer. The process of searching for genetic mutations in an affected individual is a lengthy and expensive process that is not always informative. This is because a number of breast cancer susceptibility genes remain unidentified and a large proportion of genetic mutations in known genes are not able to be identified using current techniques.

Unaffected women who are eligible for and choose to undergo predictive genetic testing, receive thorough preparation and support during the process. It usually involves two initial sessions with a specialist geneticist to gain appropriate information about the test and to discuss their expectations and worries. Then there is a “cooling off” phase of at least four weeks to give the individual time to make a final decision about taking the test, before the blood sample is taken. Results are generally given face-to-face and appropriate follow-up and psychological support can be arranged.

The results of a genetic test whether positive or negative can have a number of important implications for the individual concerned. These include making informed choices about clinical surveillance, prophylactic surgery and trials of chemoprevention, psychological well-being, family relationships, treatment of breast cancer (Eccles et al., 2000) and legal issues such as life assurance. For example, if a woman is found to carry the genetic mutation that has been identified in her family (i.e. a positive result), she can be offered a level of screening that is appropriate for her risk together with prophylactic surgery and participation in a chemoprevention trial. In contrast, a negative test result often means that additional breast cancer screening out with the National Breast Screening Programme is not warranted.

1.4.4 Reducing the risk of breast cancer

In the absence of firm evidence regarding lifestyle factors, there are effectively only two ways in which the risk of breast cancer may be reduced: prophylactic surgery and chemoprevention by anti-oestrogen drugs.

In the U.K, prophylactic mastectomy and oophorectomy are usually only offered to women at high risk of developing breast cancer and involve thorough

preparation and support. Prophylactic mastectomy has been shown to be associated with at least a 90% decrease in the breast cancer incidence in 639 women at moderate or high risk of developing breast cancer (Hartmann et al., 1999). Rebbeck et al. (1999) found that bilateral prophylactic oophorectomy was related to a decrease in the risk of breast cancer in 43 women with a mutation in BRCA1.

Anti-oestrogen drugs such as Tamoxifen and Raloxifene are commonly used to treat women already diagnosed with breast cancer. A meta-analysis of randomised trials has shown that Tamoxifen can nearly halve the risk of contralateral breast cancer in women already diagnosed with early-stage breast cancer (Early Breast Cancer Trialists' Collaborative Group, 1998). The use of these drugs to prevent the development of breast cancer in asymptomatic women at increased risk of the disease has not yet been licensed in the U.K outside of research trials. However, there are a number of ongoing worldwide randomised controlled trials investigating the impact of these chemopreventative agents on the development of breast cancer in women at increased risk of the disease such as the International Breast Cancer Intervention Study (IBIS).

Although evidence for the effectiveness of prophylactic surgery and chemoprevention in reducing the risk of breast cancer in women with a family history of the disease is accumulating, further research is needed to provide unequivocal evidence.

1.4.5 Familial breast cancer clinics

Major scientific advances in understanding cancer genetics and a corresponding increase in media attention to breast cancer has led to growing public awareness of family history as a risk factor for the disease. In order to meet the needs of growing numbers of women seeking information about their personal risk of breast cancer and advice about risk management, familial breast cancer clinics have been set up worldwide. The type of services that are offered by these clinics varies between and within countries, but usually includes some form of breast cancer screening.

Research has investigated the factors that motivate women to attend familial breast cancer clinics. Brain et al. (2000) found that nearly one third of 833 first time attendees of a familial breast cancer clinic were principally attending to gain information about their risk of developing breast cancer. However, a minority of participants did not want to or were unsure about receiving information about their personal breast cancer risk. Other key reasons for attending included being aware of

their family history (19%), gaining information about the risk of breast cancer in other family members (13%), alleviating worry (11%), gaining information about genetic testing (10%), receiving breast screening (7%) and gaining information about ways to prevent breast cancer (6%).

1.4.6 The Ardmillan familial breast cancer clinic

The Ardmillan familial breast cancer clinic was set up in Edinburgh in 1992 for women in South East Scotland with a family history of breast cancer. The clinic, which is now funded by Lothian Primary Care Trust, deals with a growing number of referrals whilst maintaining follow-up services for over 1,000 women, some of whom have been attending the clinic since it began.

The clinic provides a number of services through a multidisciplinary team of geneticists, genetic counsellors, genetic breast care nurses, breast surgeons and radiologists. These services include breast cancer genetic risk counselling, breast cancer screening (i.e. mammography, clinical breast examination, ultrasound), breast biopsy (i.e. fine needle aspiration), genetic testing for BRCA1/2 mutations (carried out by the South East of Scotland Clinical Genetics Service) for women at high risk of breast cancer, prophylactic surgery for high-risk women and the opportunity to participate in research such as the International Breast Cancer Intervention Study (IBIS) and the MRI Breast Screening Trial (MARIBS). The clinic offers these services according to the Scottish Executive (2001) guidelines (section 1.3.2, page 8).

As in many other familial breast cancer clinics, there is no formal provision of ongoing psychosocial support specifically for these women. However, women can usually be referred to a clinical psychologist for psychological assessment and support if required. Current guidelines suggest that psychological support should be offered to “anyone undergoing predictive testing for mutations in cancer predisposing genes known to exist in their families, anyone considering prophylactic surgery and any individual with signs or symptoms of clinically significant psychological disturbance” (Scottish Executive, 2001).

1.4.7 Summary

For the majority of women in South East Scotland estimated to have an increased risk of breast cancer, the clinical services they are offered are limited. Although a substantial proportion of these women are likely to have expected to be

offered predictive genetic testing, most are not eligible as a mutation in BRCA1 or BRCA2 has not yet been identified in an affected relative. Likewise, the majority of women will not be offered prophylactic surgery. Apart from participation in research trials, the only services most women will be offered focus on breast cancer screening, the efficacy of which remains uncertain in this population.

1.5 Psychosocial impact of breast cancer genetic risk counselling

1.5.1 Introduction

A large body of research has already started to address various psychosocial aspects of familial breast cancer risk including: the sociodemographic and psychological characteristics of women attending familial breast cancer clinics; the assessment and communication of breast cancer risk through genetic risk counselling; psychosocial and health behaviour outcomes of genetic risk counselling; decision-making about genetic testing and risk-reducing measures; the process and outcomes of genetic testing.

Of particular interest to the current work is the substantial proportion of this research which has investigated a range of psychosocial outcomes of genetic risk counselling for breast cancer in healthy women with a family history of the disease. These outcomes have included general psychological distress, breast cancer-specific distress, perceived risk of developing breast cancer, knowledge of issues relevant to breast cancer risk and adherence to breast cancer screening. Research has also explored the relationship between these outcomes and the impact of additional factors such as family bereavement from cancer.

A number of longitudinal studies have assessed these psychosocial factors usually by a self-report questionnaire before and after counselling. However, the post-counselling follow-up has generally been relatively short-term (i.e. from immediately after genetic risk counselling to 6 months post-counselling) (e.g. Lerman et al., 1995, 1996; Gagnon et al., 1996; Cull et al., 1998; Hopwood et al., 1998; Watson et al., 1998; Kent et al., 2000; Brain et al., 2002). Only a minority of studies have assessed such outcomes at least one year after genetic risk counselling (i.e. Evans et al., 1994; Cull et al., 1999; Schwartz et al., 1999a; Watson et al., 1999; Hopwood et al., 2001; Meiser et al., 2001b; Bish et al., 2002). In addition, a smaller number of studies have conducted cross-sectional surveys of women at increased risk

of breast cancer who are maintained on regular clinical surveillance (i.e. Kash et al., 1992; Valdimarsdottir et al., 1995; Lloyd et al., 1996; Zakowski et al., 1997, 2001).

The latter two groups of studies (i.e. one-year follow-up studies of genetic risk counselling, cross-sectional surveys) will be reviewed and subjected to critical analysis in the following sections according to psychosocial outcome variable.

1.5.1a General psychological distress

A number of studies have investigated the impact of breast cancer genetic risk counselling on general psychological distress using a variety of self-report measures including the Brief Symptoms Inventory (BSI), Spielberger State-Trait Anxiety Inventory (STAI), the General Health Questionnaire (GHQ), Beck Depression Inventory (BDI) and the Hospital Anxiety and Depression Scale (HADS).

Watson et al. (1999) evaluated 282 British women before breast cancer genetic risk counselling, immediately following counselling and one, six and 12 months later. Almost one third of participants were experiencing case-level distress at the 12-month follow-up ($\text{GHQ-12} \geq 3$), despite the fact that 13% of the total sample had been given some psychiatric treatment during the year that they had participated in the study. This factor may have affected levels of distress thus confounding the results. However, the authors do not report a comparison of the data from those participants who had and had not received psychiatric treatment. The prevalence of psychiatric morbidity obtained in this study compares to a reported prevalence of 30% (using GHQ-12 threshold ≥ 3) in women in the general population (Weich et al., 2001) and 36% (Plummer et al., 2000) to 50% (May, 1992) in general practice patients. Although, Watson et al. (1999) did not find any significant changes in general psychological distress between pre- and one year post-counselling, state anxiety (STAI) significantly decreased immediately after counselling. This is in contrast to the findings of Meiser et al. (2001b) who did not find any significant differences in depression or state anxiety (BDI and STAI) in 218 Australian women between pre-counselling and 12 months post-counselling.

Approximately 400 British women completed assessments prior to, immediately following and one year after breast cancer genetic risk counselling (Cull et al., 1999). The participants were only those women who were found to be at sufficiently increased risk of breast cancer to warrant clinical surveillance. The authors do not state the proportion of participants at moderate or high risk and the type of clinical services that would be offered to them. These factors may have

influenced the psychosocial outcomes of genetic risk counselling. Trait anxiety (STAI) assessed at baseline was significantly higher than a general population sample, but comparable to women attending a breast screening clinic. State anxiety (STAI) was significantly alleviated immediately following counselling and one-year post-counselling. Levels of state anxiety immediately post-counselling were comparable to a general population sample and significantly lower than breast screening samples. General psychological distress (GHQ-30) was significantly reduced immediately post-counselling, but was not significantly different from baseline at the one-year follow-up. Women with higher levels of general psychological distress prior to counselling had a greater risk of being notably distressed immediately after counselling.

Bish et al. (2002) found that in 26 British low-risk women, 76 moderate risk and 46 high risk, there were no significant differences in general psychological distress (GHQ-28 ≥ 5) or general anxiety and depression (HADS and STAI) between pre- genetic risk counselling and 2 weeks, 6 months and 12 months post-counselling. There were no significant differences between the low-, moderate- and high-risk groups on any of these measures during the 12-months. Pre-counselling, 41% of participants scored above the threshold to indicate a probable anxiety disorder, 11% indicated a probable depressive disorder and 31% were suffering from case-level general psychological distress. During the study period, 24% of participants had undergone BRCA1/2 genetic testing. The authors do not report a comparison of the data of those participants who had and had not undergone testing to check for differences on psychosocial outcomes, particularly psychological distress and perceived likelihood of carrying a genetic mutation.

Kash et al. (1992) assessed 217 American women with a family history of breast cancer who were enrolled in a breast cancer surveillance programme. It is not clear whether the participants in this study had received genetic risk counselling or how long they had been enrolled in the screening programme. Twenty-seven percent of the sample was found to be experiencing levels of general psychological distress (BSI) that would warrant psychological intervention. However, participants were assessed either before or immediately after a routine breast cancer screening appointment which may have resulted in a transient increase in distress levels.

Lloyd et al. (1996) compared 88 British women with a family history of breast cancer to 62 age-matched controls without a family history. The women with a family history had received breast cancer genetic risk counselling an average of 10.9 months previously (range = 2-25 months). About one third of the women in each group indicated levels of general psychological distress (BSI ≥ 63) that would

warrant psychological intervention. This may be an overestimate since some participants had only recently received genetic risk counselling and others may have been approaching the time of a routine breast cancer screening appointment.

The research generally shows that although breast cancer genetic risk counselling can significantly reduce general psychological distress immediately after genetic risk counselling, this reduction is not maintained up to one year post-counselling. One year after genetic risk counselling, levels of general psychological distress are similar to those experienced prior to counselling. Despite the fact that breast cancer genetic risk counselling has not been shown to be effective in alleviating general psychological distress, there is no evidence that it actually increases distress levels. However, a substantial proportion of women who undergo genetic risk counselling are still experiencing significant levels of distress up to 25 months after receiving their risk estimate.

1.5.1b Breast cancer-specific distress

Breast cancer-specific distress has been investigated in relation to genetic risk counselling using several measures including the Impact of Event Scale (IES), the Cancer Worry Scale (CWS) and the Cancer Anxiety and Helplessness Scale (CAHS).

Bish et al. (2002) observed that a significant decrease in worry about developing breast cancer (CWS) in women with a family history of the disease was maintained up to one year post-genetic risk counselling regardless of whether the participants were at low, moderate or high risk of breast cancer. However, the largest decline in breast cancer worry was from before counselling to 2 weeks post-counselling. Similarly, a significant reduction in intrusive and avoidant thoughts about breast cancer risk was observed in women one year following breast cancer genetic risk counselling (Meiser et al., 2001b).

Watson et al. (1999) did not find any significant changes in breast cancer-specific distress (CAHS, IES) in women with a family history of the disease one year after genetic risk counselling. In contrast, there was a significant reduction in the perception of breast cancer worry as problematic (CWS). However, 23% of participants indicated that they worried “frequently or constantly” about developing breast cancer at one-year follow-up and this worry was a “definite or severe problem” for 12% of the total sample. Although the authors report the proportion of participants who were found to be at high risk of breast cancer, the proportion of participants at moderate or low risk is not stated. This is important since the clinical

services they were offered were influenced by their risk status and this in turn could have affected levels of breast cancer-specific distress.

For 500 British women with a family history of breast cancer who were assessed prior to breast cancer genetic risk counselling and between 2-21 months post-counselling, worry about developing breast cancer (CWS) was not found to have significantly changed (Hopwood et al., 2001). Given the fact that some participants had been assessed only two months after counselling whereas others had been assessed after almost two years, this may have confounded the results.

Lloyd et al. (1996) showed that women with a family history of breast cancer who had received genetic risk counselling up to 25 months previously had significantly higher levels of intrusive and avoidance thoughts about breast cancer than the control group who didn't have a family history of the disease.

Research on the impact of genetic risk counselling on breast cancer-specific distress has produced contradictory results. Some studies have shown that genetic risk counselling can significantly reduce breast cancer-specific distress up to one year after counselling. In others, genetic risk counselling has repeatedly been shown to be ineffective in alleviating breast cancer-specific distress. These differences in findings may be due to variation in the procedure and content of genetic risk counselling both between and within countries. Despite these discrepancies, the research does suggest that a large number of women may be suffering from high levels of breast cancer-specific distress up to 21 months after genetic risk counselling.

1.5.1c *Perceived risk of breast cancer*

As perceived risk of breast cancer is likely to impact significantly on emotional response and risk-management choices, assessment of perceived risk has been commonly included in psychosocial studies in this area. Researchers have also investigated the relationship of breast cancer risk perception both to general psychological and breast cancer-specific distress. Various measurements of perceived risk have been employed including percentage lifetime risks, age-specific risks relative to the general population, odds ratios and categories of likelihood of developing breast cancer.

Watson et al. (1999) found that although genetic risk counselling generally improved the accuracy of perceived risk of breast cancer post-counselling, this improvement declined at one-year post-counselling. A significant association was found between perceived risk and objective risk of breast cancer up to one year post-

counselling. Immediately post-counselling, 31% of participants reported an accurate perception of their breast cancer risk, but only 17% did at one-year follow-up. The women who overestimated their risk at the one-year follow-up indicated significantly greater levels of intrusive and avoidant thoughts about breast cancer risk than the women who underestimated or correctly estimated their risk. Accuracy of perceived risk was shown to predict levels of cancer worry at baseline and one year, where over-estimators were more likely to have frequent or constant worries about breast cancer and perceive it to be a problem than the women who underestimated or correctly estimated their risk.

Accuracy of perceived risk was shown to significantly improve from baseline to immediately post-counselling for women who initially over- or underestimated their risk of developing breast cancer (Cull et al., 1999). Despite these improvements both groups of women continued to hold significantly inaccurate perceptions of their risk and this was sustained up to the one-year follow-up. In addition, perceived risk was found to increase again in the women who initially over-estimated their risk between immediately post-counsel and one year later. Over-estimators only showed a significant reduction in state anxiety immediately post-counselling. There was no relationship between accuracy of perceived risk and state anxiety at the one-year follow-up. The study did not provide any evidence that a change in perceived risk was related to an alteration in general psychological distress.

Evans et al. (1994) assessed perception of breast cancer risk in 200 British women both prior to and at least one year after genetic risk counselling. There were significant improvements in the accuracy of perceived personal risk of developing breast cancer at the one-year follow-up. However, the effect of these improvements on levels of psychological distress was not assessed.

Bish et al. (2002) found that breast cancer genetic risk counselling did not significantly alter perceived risk of developing breast cancer up to 12 months post-counselling. However, a comparison of the mean values one year post-counselling showed that the women at low risk accurately perceived the least risk and women at moderate risk perceived a lower risk than the women at high risk.

The accuracy of perceived risk of breast cancer was found to significantly improve 2-21 months post-counselling with 42.1% giving a correct estimate, 28.8% underestimating and 23.3% overestimating their risk (Hopwood et al., 2001). Women who originally overestimated their breast cancer risk experienced a significant decrease in worry about developing breast cancer. Three of the 500 participants had undergone genetic testing for breast cancer susceptibility during the study period and one was found to carry a genetic mutation. Although this was only a small proportion

of participants, their psychosocial outcomes may be different from those who had not undergone testing which may have influenced the overall results.

Meiser et al. (2001b) observed that although the majority of women correctly perceived their risk of breast cancer one year post-counselling, 31% continued to overestimate their risk and 14% still underestimated their risk. The reduction in intrusive and avoidant thoughts about breast cancer risk were found to be predicted by improvements in the perceived risk of developing breast cancer.

In contrast, Lloyd et al. (1996) found that only 19.4% of the women who had attended breast cancer genetic risk counselling, perceived their risk of breast cancer accurately, whereas 48.4% underestimated and 17.7% over estimated their risk. Accuracy of perceived risk was not found to be related to the time since genetic risk counselling. Perception of a high risk of breast cancer was related to greater levels of intrusive and avoidance thoughts about breast cancer.

Although research has provided evidence that breast cancer genetic risk counselling can significantly improve the accuracy of a woman's perceived personal risk of developing the disease, the extent of this improvement is not necessarily sustained. A considerable proportion of the women who attend breast cancer genetic risk counselling do not form an accurate perception of their risk up to 25 months post-counselling. There is evidence that the accuracy of perceived risk of breast cancer is related to levels of breast cancer-specific distress. Women who initially perceive themselves to be at high risk or who overestimate their risk may experience greater or more sustained reduction in breast cancer-specific distress following genetic risk counselling. However, this group of women are still likely to be suffering from heightened levels of breast cancer specific distress in the longer-term.

1.5.1d Knowledge of issues relevant to breast cancer risk

Of the few studies that have investigated knowledge of breast cancer genetics in women with a family history of the disease (i.e. Lerman et al., 1996; Wonderlick & Fine, 1997; Cull et al., 1998; Bluman et al., 1999; Meiser et al., 2001a & b), only one study has assessed this knowledge one-year post-genetic risk counselling (i.e. Meiser et al., 2001b).

A 9-item true-false scale, adapted from a previous study (i.e. Lerman et al., 1996) was used to assess knowledge of the inheritance of breast cancer susceptibility, the associated risks, effectiveness of screening and risk-reducing methods in 218 Australian women (Meiser et al., 2001b). Responses to eight of the nine items showed significant improvements at one-year post-counselling. In contrast, responses

to the item “mammography will always detect breast cancer” did not significantly improve. Although total knowledge scores significantly improved between assessments, knowledge post-counselling was generally incomplete. The proportion of participants able to give to correct response at the one-year follow-up, to each of the knowledge items ranged from approximately 35-90%. Less than half of participants were able to give the correct response to two of the nine items (i.e. “a genetic test for breast cancer will also detect other abnormalities”, “the gene for breast cancer can also increase the risk for other cancers”). There was no evidence that knowledge at the one-year follow-up was related to general or breast cancer-specific distress. There are a number of limitations with the assessment of knowledge in this study. The internal consistency of the scale was relatively low (i.e. alpha coefficient = 0.59) in comparison with recommended levels (i.e. 0.8 or above, Bryman & Cramer, 1997). This suggests that further psychometric development and testing of the scale is needed. Given the fact that this was a multi-centre study conducted in 20 different clinics across five Australian states, the content of the genetic risk counselling sessions may have varied greatly. This may have affected the psychosocial outcomes of the study, particularly in terms of participants’ knowledge.

This study provides evidence that despite improvements in knowledge following genetic risk counselling, understanding of some of the key pieces of relevant information was markedly lacking up to one year later.

1.5.1e Screening adherence

Several studies have assessed the impact of genetic risk counselling on adherence to mammography, clinical breast-examination and breast self-examination.

Lloyd et al. (1996) found that 90% of women with a family history of breast cancer reported performing breast self-examination 2-25 months after attending genetic risk counselling compared to 76% of the control group without a family history of the disease. 66% of the women with a family history of breast cancer stated they performed breast self-examination every month, as recommended, and 40% reported they performed breast self-examination more often since attending for genetic risk counselling.

Schwartz et al. (1999a) conducted a randomised controlled trial involving 430 American women aged 40-75. It compared breast cancer genetic risk counselling with a control intervention consisting of general health education where risk assessment was not provided. Self-reported adherence to mammography was similar

in both groups at the one-year follow-up providing evidence that genetic risk counselling does not improve adherence to mammography in women already recommended to have an annual mammogram from age 40 (American Cancer Society, 2000). Genetic risk counselling was also shown to result in decreased use of mammography in women who were less well educated which the authors suggest could be due to the misinterpretation of receiving a lower risk estimate than they had expected. These findings may be limited by the fact that adherence to mammography was based on self-reports and was not verified by medical records. In addition, the authors did not consider the social desirability of reporting adherence to mammography in this group of women.

Meiser et al. (2001b) observed a slight decrease in the proportion of women adhering to recommendations for mammography and a significant decrease in adherence to clinical breast-examination one year after genetic risk counselling. Adherence to mammography and clinical breast-examination at one-year was relatively high, with 86% of the sample reporting adherence to either form of screening. Although only half of the sample reported performing breast self-examination at least monthly one year after genetic risk counselling, this was a slight improvement in the proportion of women who reported adherence to breast self-examination prior to counselling. In contrast to previous research (i.e. Schwartz et al., 1999a), women with lower levels of education were more likely to adhere to mammography than women with higher levels of education.

Research has also evaluated the effect of attending for routine breast cancer screening on psychological distress in women with a family history of the disease and the effect distress on adherence to screening.

Valdimarsdottir et al. (1995) compared levels of psychological distress in 26 American women with a family history of breast cancer who were enrolled in a breast cancer surveillance programme and 27 women without a family history of the disease who were not attending such a programme. The women with a family history were assessed immediately prior to a routine mammography, all received normal results the same day and they were assessed a second time one month later. The timing of the control group's assessments was matched with the women undergoing mammography. Acute psychological distress, which was at a high level prior to mammography, was alleviated one month later. The women with a family history had significantly higher levels of general psychological distress and intrusive thoughts about breast cancer than the control group both prior to mammography and one month later after they had received their normal results. The number of participants in this study is small which may limit the generalisability of the findings.

The authors do not state how long participants had been enrolled in the screening programme. Familiarity with breast cancer screening could have impacted on levels of psychological distress. This limitation also applies to two additional studies that selected participants from the same subject pool (i.e. Zakowski et al., 1997; 2001).

Zakowski et al. (1997) compared 46 American women with a family history of breast cancer enrolled in a screening programme and 43 women without a family history of breast cancer who were not enrolled in such a programme. The women with a family history were assessed immediately prior to an annual mammography and 4-8 weeks later after they had received their normal results. The control group was assessed at similar intervals. There were significantly greater levels of intrusive and avoidant thoughts about breast cancer in the women with a family history of the disease than the control group at both assessments. However, there was no evidence to suggest that undergoing mammography temporarily elevated levels of breast cancer-specific distress.

In women with a family history of breast cancer enrolled in a surveillance programme, high levels of cancer-related anxiety were shown to impair adherence to clinical breast-examination as only 69% of the sample adhered to clinical breast-examination recommendations (Kash et al., 1992). Similarly, high levels of general anxiety reduced adherence to breast self-examination, as only 40% reported performing breast self-examination on a monthly basis.

Therefore, research has not yet provided unambiguous evidence that genetic risk counselling improves adherence to any form of breast cancer screening, although there is some data to suggest improved adherence to breast self-examination. Studies have also shown that attendance for routine breast cancer screening is associated with a period of heightened general psychological distress and sustained high levels of breast cancer specific distress which can both interfere with adherence to breast cancer screening. There is evidence for an optimum level of anxiety in terms of adherence to breast cancer screening, where higher or lower levels of anxiety could impair adherence.

1.5.1f *Other factors that may affect distress*

A number of other factors have been investigated in terms of their impact on general and breast cancer-specific distress including bereavement and certain dispositional characteristics.

Zakowski et al. (1997) found significantly higher levels of breast cancer specific distress and perceived risk of breast cancer in women with a family history

of breast cancer whose parent had died from cancer than in those women who hadn't experienced such a bereavement. Levels of breast cancer-specific distress in the latter group were comparable to the control group without a family history of the disease or death of a parent from cancer. Recency of bereavement was not shown to be related to levels of breast cancer-specific distress or perceived risk of breast cancer. The authors suggest that the death of a parent from cancer may heighten the perceived risk of breast cancer and the belief that breast cancer is an incurable disease. However, these results should be interpreted with caution as the number of participants who had not experienced the death of a parent from cancer was relatively small (i.e. 16).

Bereavement due to breast cancer had also been linked to breast cancer-specific distress in women with a family history of the disease prior to breast cancer genetic risk counselling (Hopwood et al., 2001). Women who were aged less than ten years when their mother had died from breast cancer reported significantly less worry about cancer than the women bereaved at any other age.

Zakowski et al. (2001) provided evidence that having a tendency to express emotions externally may moderate general psychological distress in women with a family history of breast cancer. One hundred and four women were assessed 1-2 months after receiving the normal results of a routine mammography. Emotional expressivity was proposed to buffer the distressing effect of having intrusive thoughts about breast cancer. The measure of emotional expressivity did not distinguish between the type of emotions that were expressed (e.g. positive and negative) but assessed a general tendency to express emotions outwardly. It is therefore difficult to infer from these results the particular type of emotional expression that may be adaptive for these women.

Cull et al. (1999) found evidence to suggest that having an external or chance locus of control about your health could be related to heightened perceptions of breast cancer risk and higher levels of distress in women attending breast cancer genetic risk counselling.

There is evidence that bereavement from cancer in the family and the age at which that occurred, emotional expressivity and health locus of control affect levels of distress in women with a family history of breast cancer.

1.5.2 Summary: critique of the literature on the psychosocial impact of breast cancer genetic risk counselling

This review has identified several caveats concerning the research conducted to date on the psychosocial impact of breast cancer genetic risk counselling. These include: lack of long-term follow-up, heterogeneous samples with respect to risk and little understanding of the needs of women with an increased risk of breast cancer in terms of information and support.

Although a large number of longitudinal studies have investigated the psychosocial effects of breast cancer genetic risk counselling, the post-counselling follow-up has tended to be relatively short-term. Of these studies, psychosocial outcomes have often been assessed up to one year following counselling (i.e. Evans et al., 1994; Cull et al., 1999; Schwartz et al., 1999a; Watson et al., 1999; Meiser et al., 2001b; Bish et al., 2002) with few published studies to date extending beyond this follow-up (i.e. Hopwood et al., 2001). Even then follow-up has only extended to 21 months in some but not all participants in the study (Hopwood et al., 2001). In addition, several cross-sectional surveys assessing psychosocial factors have been carried out of women at increased risk of breast cancer who are maintained on regular clinical surveillance (i.e. Kash et al., 1992; Valdimarsdottir et al., 1995; Lloyd et al., 1996; Zakowski et al., 1997, 2001). However, these studies have not always specified whether the participants had received genetic risk counselling or how long they had been attending routine clinical surveillance. Of those studies that had provided such details (i.e. Lloyd et al., 1996), the participants were a heterogeneous sample with respect to the time elapsed since genetic risk counselling which ranged from 2-25 months (Lloyd et al., 1996).

These longitudinal or cross-sectional studies have tended to investigate samples of women that vary greatly both in their objective risk of breast cancer and their eligibility for genetic testing or risk-reducing measures.

It is then clear that there is a lack of knowledge about the psychosocial consequences of living with an increased risk of breast cancer over a period of years, particularly among British women who are not eligible for genetic testing or prophylactic surgery. Indeed, this lack of research has been acknowledged in the literature, although it has not yet been addressed: "Little is known of the long-term psychological effect of perceiving that one has an increased risk for breast cancer" (Chalmers et al., 2001).

The literature to date also lacks an investigation of the needs of all women at increased risk of breast cancer in terms of information and support and what type of

services would be most effective in meeting these needs. Again, this deficit has recently been acknowledged in the literature (i.e. Chalmers et al., 2001) and is beginning to be addressed. This lack of understanding is particularly relevant regarding women at increased risk of breast cancer who are not eligible for genetic testing or prophylactic surgery. The literature has suggested that these women require general information about risk factors for breast cancer, including hereditary factors and breast cancer screening (Ondrusek et al., 1999). However, “the optimal means of educating this large and heterogeneous group of women is unknown” (Ondrusek et al., 1999).

1.5.3 The uncertainty of having an increased risk of breast cancer

Uncertainty has been defined as “a condition of not knowing indisputably – being unreliable, changeable or erratic” (Bottorff et al., 1998). Although the process of breast cancer genetic risk counselling aims to reduce some of the uncertainty of having a family history of breast cancer, a large amount of uncertainty still remains for these women.

Breast cancer genetic risk counselling provides an individual with a risk estimate representing the probabilities of just two possible outcomes (i.e. developing breast cancer or not developing breast cancer). However, the nature of probabilities means that the risk estimates are themselves “essentially uncertain” (van Zuuren et al., 1997). They cannot provide a definitive answer about: whether an individual will ever develop breast cancer; at what age they will be diagnosed; their prognosis; if their children will also be at increased risk of the disease.

There is still controversy about the value of breast cancer screening practices recommended to women who are at a significantly increased risk of the disease. Until scientific advances provide effective methods to prevent the development of breast cancer, these women face the prospect of years of clinical surveillance.

Therefore, these women face multiple uncertainties concerning their risk of developing breast cancer and the screening methods currently offered to them.

A review of the literature on the psychosocial effects of uncertainty in acute illness has provided strong evidence of relationship between greater uncertainty and higher levels of psychological distress and this has been shown to continue over time (Mishel, 1997). Numerous causes of uncertainty in acute illness have been documented in the literature. Several of these causes may be particularly relevant to the uncertainty of having an increased risk of breast cancer: perceived control, social support and the provision of relevant information. Murphy (1999) has proposed that

anxiety is just one of a number of different ways that individuals deal with the uncertainty associated with having a family history of cancer: anxiety, fatalism, denial, screening, information and genetic testing.

Given these multiple uncertainties, there is clearly a corresponding risk of psychological morbidity in women with an increased risk of breast cancer.

Although it is currently not realistic to remove all the uncertainty that is associated with having an increased risk of breast cancer, it may be possible to reduce some of the uncertainty and render the remaining uncertainty easier to manage. It is known that in acute illness uncertainty can be exacerbated if sources of information such as health professionals are not readily available (Mishel, 1997). Psychoeducational interventions have been shown to be effective in managing the uncertainty experienced by cancer patients (e.g. Mishel et al., 2002) and could perhaps meet the needs of women living with an increased risk of breast cancer.

1.6 The current work

1.6.1 Rationale for area of research

A number of considerations from the psychological literature and from clinicians involved in the management of women at increased risk of breast cancer informed the research questions addressed in this thesis.

Firstly, there is a lack of research on the psychosocial effects of living with an increased risk of breast cancer for a number of years in women at increased risk of breast cancer who are not eligible for genetic testing or prophylactic surgery. This group of women form a large proportion of the women estimated to be at increased risk of the disease and their numbers are likely to continue to grow.

Secondly, it is clear that these women have to deal with continuing multiple uncertainties concerning their increased risk of breast cancer. This could have important implications in terms of psychological distress, the development of health anxiety and the overall impact on their daily life. Research in individuals who are acutely ill has already provided evidence of an association between greater degrees of uncertainty and psychological distress.

Thirdly, research in women with an increased risk of breast cancer has shown that a substantial proportion are experiencing significant levels of general psychological and breast cancer-specific distress up to 25 months after attending for

breast cancer genetic risk counselling. There could be a number of important implications both for individuals, their families and the clinical services if chronic psychological distress was found to be prevalent in women who have been living with the knowledge of an increased risk of breast cancer for a number of years. Research in American women with a family history of breast cancer has indicated that high levels of distress are associated with non-adherence to breast self-examination (e.g. Kash et al., 1992), clinical breast-examination (e.g. Kash et al., 1992) and mammography (e.g. Lerman et al., 1993). If distress is also shown to interfere with screening in British women and this surveillance is proven to be effective in this population, chronic distress may elevate the risk of death from breast cancer for those already estimated to be at increased risk of the disease. In addition, there may be important implications for future generations within the same family. Women who are living with an increased risk of breast cancer and who are chronically distressed may represent maladaptive role models for the next generation who are also likely to face living with this constant threat.

Fourthly, there is a lack of understanding about the needs of these women in terms of information about issues relating to their increased risk of breast cancer and support to help them cope. The general information they were given during genetic risk counselling several years ago (e.g. about breast cancer genetics, breast cancer screening methods) is now likely to be out-of date. The current clinical service, whose main focus is the provision of regular clinical surveillance, does not formally provide information or psychosocial support for these women. Clinicians at the Ardmillan familial breast cancer clinic are concerned that insufficient time is available during routine clinic appointments to address the possible needs of these women for general information and support. However, it would be important to meet these needs in an efficient and cost-effective manner which would not place further pressures on the resources of the clinic.

1.6.2 Outline of research methodology

The current work was intended to investigate the psychosocial effects of living with an increased risk of breast cancer in women who have been attending the Ardmillan familial breast cancer clinic for regular clinical surveillance for at least two years.

This work was initiated with an exploratory qualitative study to investigate the psychosocial effects of living with an increased risk of breast cancer and to confirm the concerns about these women's needs for information and psychosocial

support that were not being met by the current clinical service. The novel methodology of telephone focus groups was adopted which is described in Chapter 2.

The plan was then to conduct a larger cross-sectional survey to obtain quantitative data about these needs. This type of methodology has been successfully used in several studies of women at increased risk of breast cancer who are maintained on regular clinical surveillance (i.e. Kash et al., 1992; Valdimarsdottir et al., 1995; Lloyd et al., 1996; Zakowski et al., 1997, 2001).

The data collected in the cross-sectional survey were intended to inform the development of a psychoeducational intervention that aimed to meet the needs of these women. This intervention was proposed to be evaluated in a randomised controlled trial, a methodology that has been used to effectively evaluate psychological interventions in women with a family history of breast cancer (e.g. Gagnon et al., 1996; Lerman et al., 1996; Cull et al., 1998; Schwartz et al., 1998; Watson et al., 1998; Audrain et al., 1999; Kash et al., 1999).

1.6.3 Rationale for measures to assess psychological distress

Psychological distress is a broad term that is used in this thesis to describe a number of constructs including general psychological distress, general psychological morbidity and breast cancer specific-distress (i.e. cancer worry, intrusive and avoidant thoughts about breast cancer). The research intends to investigate the range of levels and types of psychological distress that are being experienced by women living with an increased risk of breast cancer. Of particular importance is the investigation of high levels of distress that may indicate psychological morbidity. Such levels of distress are likely to have a considerable negative impact on an individual's daily life which therefore suggests that treatment should be offered.

The cross-sectional survey employed a measure of general psychological distress (i.e. GHQ-12, Goldberg & Williams, 1991). This can screen for clinically significant distress using a threshold score and therefore provides an estimate of the prevalence of psychological morbidity (further details of the GHQ-12 are included in Chapter 4, Section 4.6.4a, page 88). The psychological literature has shown that the prevalence of general psychological morbidity in women with a family history of breast cancer up to one-year post-counselling is similar to that found in women in the general population. However, general psychological morbidity has not been assessed in women who have been living with an increased risk of breast cancer for several years. It would be important to compare this prevalence to the existing literature to determine the need for psychological intervention in this group of women.

In addition, the cross-sectional survey used the somatic symptoms subscale from the GHQ-28 (Goldberg & Hillier, 1979) for exploratory purposes (further details of this subscale are included in Chapter 4, Section 4.6.4b, page 88). The use of this subscale is not intended to provide a direct measure of general psychological distress but rather gives an estimate of the frequency that somatic symptoms were reported among participants. It was hoped that this type of data would enable us to determine whether increasing vigilance to the health of these women resulted in greater levels of somatic symptoms.

In the final study, the randomised controlled trial of the psychoeducational intervention, the key psychological distress outcome was cancer worry. The results of the cross-sectional survey suggested that the assessment of breast cancer-specific distress was more relevant than general psychological distress in women living with an increased risk of breast cancer for several years (as levels were higher compared to general population comparison data). However, as yet no clinical thresholds for measures of breast cancer-specific distress have been derived to indicate clinically significant levels of distress. The 6-item Cancer Worry Scale (Watson et al., 1998) was selected as the key outcome of the trial. It has been shown to be psychometrically sound, sensitive in and relevant to women at increased risk of breast cancer (further details on the scale are included in Chapter 6, Section 6.10.2a, page 151). Although clinical thresholds for the Cancer Worry Scale have not yet been derived, statistically significant reductions in scores may be clinically meaningful, although further research would be needed to determine the extent of this importance.

1.6.4 Summary

There is a clear rationale for investigating the psychosocial effects of living with an increased risk of breast cancer for several years and for the measures used to assess psychological distress. The research presented in this thesis was conducted as a series of three studies using different methodologies.

The first exploratory study formed the basis of and directed the design of subsequent studies. It was conducted using the novel methodology of telephone focus groups which is reviewed in the following chapter.

Chapter 2: Review of the Telephone Focus Group Methodology

2.1 Focus groups

2.1.1 Background to focus groups

Focus groups were originally derived from a methodology developed by Robert Merton during the 2nd World War. Then a social researcher, Merton became dissatisfied with the interviewing procedures that were being adopted in radio research, so he decided to develop a new interviewing technique which could be used with both individuals and groups (Merton, 1987). This new technique was soon recognised as the “focussed interview”. Even at that stage, Merton was promoting his “qualitative focussed group-interviews” as “sources of new ideas and new hypotheses” (Merton, 1987). Following the launch of the “focussed interview” (Merton & Kendall, 1946) in the American Journal of Sociology, Merton’s new methodology did not seem to be employed widely by social researchers. However, this initial reaction by researchers was in no way to predict the later widespread use of the “focus group”, derived from Merton’s work.

2.1.2 What is a focus group?

Each of the definitions in Table 2 describes some of the central characteristics of a focus group: qualitative methodology (i.e. Merton, 1987; Tobin, 1996), group interaction (i.e. Kitzinger, 1995; Morgan, 1997; Tobin, 1996), group interview (i.e. Kitzinger, 1995), gaining insight into a specific topic (i.e. Merton, 1987; Morgan, 1997).

Vaughn et al. (1996) identify the following central elements of focus groups:

- The aim of a focus group is to elicit of the opinions of a selected group of individuals on a specific topic.
- The group is fairly homogeneous, consisting of a small number of members (usually 6-12).
- A trained facilitator uses a prepared guide consisting of questions and probes to elicit the participants’ responses.
- Focus groups generate qualitative, not quantitative data, which therefore cannot be generalised to a wider population.

Table 2: Definitions of a focus group

“...a set of procedures for the collection and analysis of *qualitative* data that may help us gain an enlarged sociological and psychological *understanding* in whatsoever sphere of human experience” (Merton, 1987).

“Focus groups are a form of *group interview* that capitalises on *communication* between research participants in order to generate data” (Kitzinger, 1995).

“The focus group is a *qualitative* information gathering technique that capitalizes on stimulated *interaction* in a small group discussion” (Tobin, 1996).

“The hallmark of focus groups is their explicit use of *group interaction* to produce data and *insights* that would be less accessible without the interaction found in a group” (Morgan, 1997).

Of these central elements, group interaction could be regarded as the key feature of the focus group methodology. Unlike some of the other types of qualitative research tools, focus groups may be seen to have some of the features of quantitative research methods such as planning and structure, whilst maintaining their flexibility in encouraging group interaction (Vaughn et al., 1996). Focus groups do not use the group setting simply as an efficient means of data collection, but rather utilise group interaction as a distinct part of their methodology (Kitzinger, 1995). Although focus groups can be described as a type of group interview, the emphasis is not on a question-response format, but rather on the group interaction. Participants may be encouraged to contribute more to an active group setting, than for example, they would in a one-to-one interview. As Morgan (1997) suggests: “...it is the researcher’s interest that provides the focus, whereas the data themselves come from the group interaction”. Group interaction may encourage participants to investigate and clarify their own opinions. It may also encourage participants to voice their opinions using everyday forms of interaction such as jokes and anecdotes (Kitzinger, 1995). As Kitzinger (1995) suggests, this may add to our understanding of a particular issue because “Everyday forms of communication may tell us as much, if not more, about what people know or experience”. She goes on to add that “In this sense focus groups reach the parts that other methods cannot reach, revealing dimensions of understanding that often remain untapped by more conventional data collection techniques”.

Focus groups also seem to offer incidental benefits to participants that are a result of the focus group methodology and not part of the research aims. For example, Kitzinger (1995) suggests that mutual support may be gained in the group through participants expressing common feelings. The benefit that participants may gain from attending a focus group is similar to that which they may gain from attendance at a support group (Ferrell et al., 1997). In addition, Morgan (1995) suggests that psychological incentives can be offered to participants when they are offered the opportunity to voice their opinions on topics that may affect them. In this way, focus groups can be empowering for some participants, particularly if they are viewed as experts on a specific topic and if the research is applied in nature as participants can realistically perceive their contributions making a difference in the future (Gibbs, 1997).

Focus groups do tend to be a less time consuming method of data collection, than for example, developing and implementing a valid and reliable measure. This fact remains, even though a substantial amount of time is necessary to prepare the focus group guide and to train the moderator. However, the turnaround in data collection is relatively quick as a large amount of information can be elicited in short amount of time. Therefore, the focus group method is an efficient means of determining the range of experiences among a group of people (Seals et al., 1995).

2.1.3 The use of focus groups in psychological research

Although focus groups have long been used in market and business research, they have only more recently been employed as a research tool in areas such as psychology, health education and communication. It has been suggested that their recent popularity, particularly in psychological research, stems from the growing need to identify the opinions of “key stakeholders” (Vaughn et al., 1996). As psychological research has begun to embrace qualitative methodologies, so the investigation of research tools that have the potential to offer greater insight into key issues has grown.

One of the important features of focus groups, which is particularly relevant to psychological research, is that they provide insight into emotions connected to the specific issues of interest (Vaughn et al., 1996). The focus group methodology is ideal for investigating the reasons behind the way people think (Kitzinger, 1995). As Gibbs (1997) states: “The main purpose of focus group research is to draw upon respondents’ attitudes, feelings, beliefs, experiences and reactions in a way in which would not be feasible using other methods”.

The focus group methodology has been used in psychological research in a number of ways including exploratory research, validation of the data collected using other methodologies, service evaluation and development, and the development of interventions and instruments. These focus group studies have involved a variety of participants including women with a family history of breast or ovarian cancer (e.g. Pasacrete, 1999; Ryan & Skinner, 1999; Tessaro et al., 1997).

2.1.3a Exploratory research

In order to explore the beliefs about breast cancer risk and preferences for genetic risk counselling, Ryan & Skinner (1999) conducted focus groups with 29 women who had a first-degree relative with breast cancer. The qualitative results contained nine main themes: breast cancer detection; information about risk; beliefs about risk factors; beliefs about relatives' risk; desire for information; misunderstanding about risk factors; interest in genetic risk counselling; preferences for genetic risk counselling; genetic testing. The findings particularly highlighted areas of misunderstanding about breast cancer risk such as risk-reduction through lifestyle changes together with the need for information about personal risk of breast cancer and risk management. Therefore, the study had important implications in terms of the information provided during genetic risk counselling which required further investigation.

2.1.3b Validation of data

Ferrell et al. (1997) investigated quality of life issues in long-term breast cancer survivors. Twenty-one breast cancer patients who had been originally diagnosed between 16-71 months previously initially took part in individual interviews to identify personal concerns regarding their quality of life. Eleven of the same women and five other breast cancer patients then participated in one of three focus groups which were designed to validate the data collected from the one-to-one interviews. The concerns identified by the focus groups were found to fall into four general areas of well-being (i.e. physical, psychological, social, spiritual). In addition, the participants gave advice to other women newly diagnosed with breast cancer. The findings of the study had significant implications for clinical services and future research which the authors planned to confirm in a larger quantitative study.

2.1.3c Service evaluation and development

Seals et al. (1995) conducted eight focus groups to investigate the needs and concerns of 46 women with HIV/AIDS with regards to the current provision for them within the social services. A range of needs was identified through the focus groups, which could then be addressed by the appropriate organisations.

Similarly, Marcenko & Samost (1999) used focus groups to investigate the experience of mothers who were living with HIV/AIDS. They recruited 40 of these women to take part in one of six focus groups designed to investigate their opinions about the current structure of support services. Recommendations to the providers of these services could then be made from the issues that were raised during the focus groups.

In order to plan and develop new services and expand on existing services for breast cancer patients, Tobin (1993) conducted 48 focus groups with breast cancer patients, asymptomatic women and medical professionals. The discussions centred on the process from detecting breast cancer to surgical options, decision-making about other treatment options and breast cancer support services. The insight gained through this study could then be used to develop services that were directly addressing the needs of these women.

2.1.3d Intervention development

Borgers et al. (1993) utilised focus groups as part of a study combining several different methodologies to explore “the information-seeking behaviour of cancer outpatients”. Six focus groups were used to identify the kinds of reasons why cancer outpatients seek information during a consultation with their specialist. The study aimed to provide sufficient insight to enable an educational intervention to be developed.

Tessaro et al. (1997) also used the focus group methodology to design an intervention which was aimed at helping women make informed decisions concerning BRCA1 genetic testing. Breast cancer patients and asymptomatic women with affected relatives discussed their knowledge and concerns about genetic testing and their potential support needs during the decision-making process. The findings from the focus groups highlighted several possible areas for intervention including the provision of information both for these women and for the general public, the involvement of physicians in the decision-making process and the effect of genetic testing on relationships within the family.

2.1.3e Instrument development

Three focus groups of 4-6 women at increased risk of breast/ovarian cancer were conducted as part of the initial process of developing an instrument to screen these women for susceptibility of significant psychosocial problems (Pasacrete, 1999). The results highlighted several possible risk factors on which further research can build. The author commented: "The focus group method provided an excellent avenue for beginning exploration regarding psychosocial issues associated with being at increased risk for developing breast and ovarian cancer".

2.1.4 Preparing focus groups

There are a number of interdependent practical issues to consider when preparing to undertake focus group research which include selecting participants, deciding on the size, number and duration of the focus groups and developing a moderator guide to outline the structure of the groups. The purpose and aims of the research should inform all these issues (Vaughn et al., 1996).

2.1.4a Participant selection

Since the data collected from focus group research comes directly from the participants, identifying, selecting and recruiting appropriate participants is vital to the success of the research. Focus group studies often use a purposive sampling technique to select participants (where selection is based on criteria that aim to predict how valuable each participant's contribution would be). Participants may be selected at random if there is a large enough group of suitable recruits (Vaughn et al., 1996).

Although it is often recommended in the focus group literature that the participants in a focus group should form a homogenous group as far as their sociodemographic characteristics are concerned (e.g. Greenbaum, 1998), Vaughn et al. (1996) suggest that a heterogeneous group of participants may be more useful when focus groups are used in exploratory research. Potential participants should form a homogenous group in the sense that they all should share the same experience which is at the heart of the research (Asbury, 1995). Vaughn et al. (1996) recommend that when age is not an important factor, a relatively wide range in the age of participants will be of benefit to the study. They also suggest that focus group participants should be strangers (Vaughn et al., 1996), as the extent of acquaintance

among participants is likely to affect the interaction within the group (Morgan, 1997). However, where any differences in the dynamics of the group are not of great importance to the research, more practical issues such as the availability of participants may influence this choice (Morgan, 1997).

An additional factor to consider concerns the preparation of the participants themselves. Although participants should be made aware of the general purpose and topic of the discussion beforehand, the researcher should not inform them of the specific research questions to prevent sensitisation to the focus group issue (Vaughn et al., 1996).

2.1.4b Focus group size

The size of a focus group is important as it affects the amount of opportunity participants can contribute to the discussion which in turn influences the data collected. The literature presents a range of recommendations of focus group size; 4-8 (Kitzinger, 1995), 4-12 (Tang & Davis, 1995), 6-10 (Morgan, 1997), 6-12 (Asbury, 1995; Vaughn et al., 1996), 8-10 (Greenbaum, 1998; Tobin, 1996).

Tang & Davis (1995) state that: "Among the many critical issues in using focus group methods, the development of critical factors for the determination of the size of a focus group remains a focal concern ...". However, there appears to be a certain amount of uncertainty in the literature concerning the exact nature of these critical factors. For example, Morgan (1997) suggests that there are several key factors that should be considered when determining focus group size: the participants' degree of interest in the topic (which may affect their contribution to the group), the detail required from each participant, the management of participants and the level of moderator involvement required. However, other researchers suggest that the most important factor governing the number of participants in a single focus group should be the research aims (Tang & Davis, 1995). These researchers go on to propose four additional factors that can greatly ease the decision-making process. These are: the number of questions to be asked, the time designated per question, the focus group structure and its duration. Vaughn et al. (1996) simply recommend that when deciding on the focus group size, it is important to ensure that the group is not too small to prevent participants feeling that they have a duty to contribute almost continuously. Similarly, in order to allow the moderator to communicate with each participant and to ensure participants have enough time to make their opinions known, the groups should not be too large (Vaughn et al., 1996).

It has been recommended that focus groups used in an exploratory manner should involve smaller numbers of participants per group, but the number of groups should be larger (Tang & Davis, 1995).

2.1.4c *Number of focus groups*

Likewise, it can often be difficult to predict the number of focus groups that will provide sufficient information to address the aims of the research. Vaughn et al. (1996) suggest two factors that should be taken into account: the number of groups could be considered sufficient both when all the results are repetitive and can easily be predicted by the moderator and when a range of participant's experiences has been gained that allows sufficient insight into the topic of interest. Morgan (1997) describes the degree of homogeneity between participants as the most salient factor when determining the number of focus groups to conduct. This is in addition to the degree of focus group structure and participant availability. Therefore, a greater degree of participant variability both within and between groups will usually require a larger number of groups to reach the point where no new information is generated.

2.1.4d *Duration of focus groups*

Although it is generally recommended in the literature that focus groups should take between one and a half to two hours (e.g. Asbury, 1995; Tobin, 1996; Vaughn et al., 1996), the duration of focus groups should be influenced by the nature of the topic to be discussed, the size of the group and the homogeneity of the participants within the group (Vaughn et al., 1996).

2.1.4e *Moderator guide*

Developing a good moderator guide has been described as "vital to an effective focus group project" and requires care and consideration comparable to that given to the development of a quantitative questionnaire (Greenbaum, 1998). "The purpose of the moderator's guide is to serve as a map to chart the course of the focus group interview from beginning to end" (Vaughn et al., 1996). It is usually a form of semi-structured interview plan consisting of main questions and probe questions. The latter are used to clarify responses to a preceding question, provide a prompt for further exploration of topics and can assist in redirecting the discussion (Asbury, 1995). Tobin (1996) recommends that a well-prepared moderator guide usually comprises of the following sections:

- Introduction - where the purpose of the study is explained, both the moderator and participants introduce themselves and some ground rules for the format of the group are set.
- General questions - to allow participants to gently ease into the group setting.
- Specific questions - to gain responses to key issues.
- Closure - to enable the moderator to ask for any additional information, and to thank the participants for taking part.

The amount of detail necessary for such a guide varies with the moderator's level of comfort and experience of conducting focus groups together with the nature of the issue to be covered (Vaughn et al., 1996). Decisions about the content of the moderator's guide concerning the structure of the focus groups, the degree of flexibility between groups and the extent to which the moderator will be involved in the discussion, should be made on the basis of the research aims (Morgan, 1997). Morgan (1997) proposes that the "funnel strategy" (where the focus group moves from a less to a more structured discussion along its duration) is a good compromise between these two contrasting approaches to moderator guide design. In this way, participants' own experiences are discussed during the early stages of the focus group, moving onto collecting their responses to questions regarding the researcher's key interests during the later stages (Morgan, 1997). This type of approach, however, can in no way be considered an easy option as changes in structure and shifts in degree of moderation can be difficult to successfully achieve (Morgan, 1997). When developing a moderator guide, some researchers such as Tang & Davis (1995) have stressed the importance of conducting pilot tests of the moderator guide to determine factors such as the amount of time to be allowed for each question and the wording of questions. Morgan (1995) also highlights the importance of carrying out pilot testing of the focus group questions through several one-to-one interviews.

2.1.5 Conducting focus groups

Sim (1998) identifies a number of reasons that contribute to the complex nature of collecting focus group data: the data should pertain to both the content and context of participant contributions, each contribution should be accurately assigned to a group member, the moderator should not be distracted from facilitating the group by the data collection procedure and the technique used to record the data should not exert any bias over participant contributions.

2.1.5a *The focus group moderator*

The moderator plays a key role in the success of a focus group. As Vaughn et al. (1996) suggest: “With the guidance of a moderator, individuals are capable of reporting on their own cognitions, feelings and behaviours in an accurate and forthright manner”. Their major role centres around directing the focus group discussion by posing questions and encouraging participation. They may also play an important role during the focus group preparation, in terms of preparing the moderator guide and recruiting participants and after the focus group, during data analysis.

In order for the participants to contribute openly to the focus group, a comfortable environment needs to be established quickly (Vaughn et al., 1996). Asbury (1995) suggests that the moderator’s hardest task may be making the participants feel comfortable.

Vaughn et al. (1996) have proposed a number of recommendations for moderating focus groups. There are a number of techniques that have been documented to assist the moderator which are often incorporated into the introduction section of the moderator guide, thus setting the tone for any subsequent discussion. These include providing the participants with a clear explanation of the purposes of the research, emphasising the value of all contributions, introducing the moderator and inviting the participants to introduce themselves to the group using their first names only. By using first names only, equality can be maintained between the participants and the moderator which will help to put the participants at ease. As it is likely that the moderator has sole responsibility for data collection, it is essential that he or she has a complete understanding of the aims of the research in order to elicit useful information from participants. However, the moderator’s knowledge of the field should not be allowed to overwhelm participants to the detriment of their contribution to the group. In contrast, detailed responses can be gained from participants by showing the moderator genuinely has insufficient knowledge of the topic area. In order to make the best use of this potentially rich data source, open-ended questions are recommended to initiate interaction. Then the moderator can use probes to invite participants to clarify or expand on their responses or to encourage quieter participants to become more involved in the discussion. The moderator should encourage every member of the group to contribute and provide them all with an equal opportunity of doing so.

An effective moderator maintains a dynamic role in a focus group (Vaughn et al., 1996). Sim (1998) identifies a specific difficulty that the moderator faces:

creating and maintaining an appropriate balance between active and passive involvement in the focus groups. Active roles include redirecting the discussion if it moves away from the topic of interest (Gibbs, 1997), generating responses if the discussion dies out and ensuring that the discussion is brought to an appropriate conclusion in the time allotted (Vaughn et al., 1996). A moderator's main passive role is to allow group interaction to continue where the discussion is running smoothly (Vaughn et al., 1996). Although they have to generate discussion on a topic connected to their research interests, they must do so without leading the group into confirming their own preconceived ideas (Sim, 1998). Moderators must both be in control of the discussion and responsive to participants (Vaughn et al., 1996).

The moderator clearly has both a demanding and challenging role, which requires particular characteristics and skills (Gibbs, 1997), some of which are inherent to a person, whilst others can be learned (Greenbaum, 1998). These include: "a superior listening ability, an excellent short-term auditory memory, well organised, quick learner, high energy level, personable, well-above-average intelligence" (Greenbaum, 1998). Moderators should also have good oral and written communication skills, be able to make conclusions and recommendations from the interpretation of the results (Greenbaum, 1998) and they must be sensitive to responses and react with genuine interest and concern (Vaughn et al., 1996). In addition, participant responses may be influenced by the demographic characteristics of the moderator such as their age, gender or ethnic group (Vaughn et al., 1996).

As "the role of the moderator is a difficult one to fulfil adequately" (Sim, 1998), it may be necessary in many cases to train the moderator, particularly if they lack experience facilitating focus groups (Vaughn et al., 1996). This may involve observing groups conducted by a more experienced moderator or conducting informal, practice groups.

2.1.5b Recording the data

It is generally recommended that focus groups are audiotaped to allow the moderator to focus their full attention on the group discussion (Sim, 1998). As this is often the principal method of recording the data, it is crucial to ensure that the quality and reliability of the recording is sufficient to allow an accurate transcription of the data. Transcription is necessary for thorough data analysis. It can help to prevent biased listening and missed data which can result from the moderator attempting to analyse the data straight from the audiotape (Henderson, 1995). In addition, the audiotape remains a valuable tool as it can act as a reference for a specific portion of

a transcript where more details about the tone or emotions associated with a particular response are required by the moderator. However, an audiotape alone does not easily lend itself to the identification of participant contributions (Sim, 1998). The researcher must either be very accurate at recognising participant voices, use a video-recorder or write notes during the group (or designate this task to an assistant) (Sim, 1998). Use of the latter two of these methods should neither discourage participants from contributing nor detract from the facilitation of the group (Morgan, 1997). Kitzinger (1995) suggests that it may be useful to collect participants' comments following the focus group either in the form of a brief questionnaire or a one-to-one interview.

2.1.6 Analysing focus groups

Analysis of the data collected from focus groups is often the greatest difficulty facing researchers who choose to adopt this methodology. It can become an overwhelming task to transform the large amount of data collected into concise, coherent results. Several authors have recognised the lack of guidance that is available for researchers concerning the analysis of focus group data (e.g. Carey, 1995; Vaughn et al., 1996; Wilkinson, 1998a). The literature reporting the results of focus group studies often provides insufficient information about the analysis process (Vaughn et al., 1996). However, the "credibility and usefulness of results will be enhanced through a careful documentation of steps and decisions in the analysis as the raw data are transformed into understandable themes and patterns" (Asbury, 1995).

Given the lack of consensus concerning the type of technique that should be used to analyse focus group results (Carey, 1995) and the researcher's desire to produce credible work, deciding on the most appropriate analytic technique is not straightforward. Analysis plans should be considered at the initial stages of identifying the aims of the study as suitable questions should not be developed without a view to how their responses will be analysed (Henderson, 1995). Asbury (1995) suggests that both the aims of the research and the objectives of the written research report will determine the most appropriate method of analysis. With regard to exploratory focus group research, the analysis process will be directed by the requirements of further research so that if, for example, the results are intended to inform the development of a subsequent intervention, then the analysis may focus on meeting these aims (Morgan, 1997).

Focus group data can be analysed by the same qualitative techniques as applied to one-to-one interviews (i.e. content or thematic analysis which can often be assisted by computer programs such as NUDIST; discursive, rhetorical or conversational analysis) (Wilkinson, 1998b).

Undertaking immediate summaries of the main issues discussed in the group and adopting appropriate methods of transcription will facilitate the subsequent analysis. Participant quotes should be used to support the focus group summary (Vaughn et al., 1996). Vaughn et al. (1996) document their own method of analysing focus group data which consists of five main stages: "identifying the big ideas (1); unitizing the data (2); categorizing the units (3); negotiating categories (4); identifying themes and use of theory (5)".

The reliability and validity of qualitative data has been omitted by many researchers. In contrast, some researchers (e.g. Appleton, 1995; Carey, 1995; Yardley, 2000) do regard these issues to be important concepts to consider when conducting qualitative research, including focus groups. However, many criteria traditionally applied to quantitative data (e.g. repeatability) to assess these concepts are not applicable to qualitative research (Yardley, 2000). Yardley (2000) proposes four key flexible principles that may act as indicators of good qualitative research: "sensitivity to context, commitment and rigour, transparency and coherence and impact and importance". Appleton (1995) attempted to address issues of reliability and validity of a qualitative study in a number of ways. Validity of the qualitative analysis of one-to-one interviews was assessed by ensuring the results were credible with some of the study participants, involving a second researcher in the analysis process to achieve consensus with the first researcher. Reliability was addressed in a number of ways including attempting to keep interview skills consistent throughout the 12 interviews (pilot interviews were undertaken to practice skills), audiotaping all interviews and writing a detailed report of the whole study process.

There is also a lack of agreement amongst researchers as to the appropriateness of assessing the inter-rater reliability of qualitative data (Armstrong et al., 1997). Inter-rater reliability can be defined as "the extent to which two reviewers reach similar conclusions from the same record" rather than multiple raters identifying the same aspects of the data from the same record (Brennan & Hays, 1992). A number of statistics assess inter-rater reliability including the Kappa statistic, which is used "when two or more judges consider the same entity and express a judgment regarding that entity" (Brennan & Hays, 1992).

2.1.7 Limitations of focus group research

There are a number of limitations of focus group research which can arise at different stages in the research process from recruiting participants to interpreting the results.

Individuals may be deterred from taking part in focus groups because they may not be very confident or articulate, they might have problems communicating or may not feel able to trust other people with personal information (Gibbs, 1997). Therefore focus group participants may be biased in terms of being more self-confident or willing to take risks than those who choose not to participate (Tobin, 1996).

As participants are speaking in the specific context of a focus group, the views they express may not necessarily be the same as those they would give during a one-to-one interview (Tobin, 1996). The opinions participants convey during the group may be shaped by the views of others and new opinions may be formed during the session (Vaughn et al., 1996). Participants may be affected by the characteristics of other group members, how the moderator phrases the questions and how secure the participants feel with the confidentiality of the group to give socially desirable responses (Vaughn et al., 1996). Participants may not necessarily make equal contributions to the focus group (i.e. every participant might not respond to every question). This can be influenced by the behaviour of the moderator or other group members together with the dynamics of the group.

Although the moderator has a key role in keeping the group members focused on the topics of interest, they should have little influence over the interactions in the group and the data that is produced (Gibbs, 1997).

Given the small number of participants and potential biases, it is not appropriate to generalise the results of focus groups research to a larger population (Vaughn et al., 1996). Further research would be warranted to confirm the findings in a larger sample.

2.1.8 Types of focus group

New methods of conducting focus groups in addition to the traditional face-to-face groups have been developed in recent years (Greenbaum, 1998). These involve the use of technologies such as videoconferencing, the Internet and the telephone and have been described by Greenbaum (1998). Videoconferencing allows observers who have an interest in the results to watch focus groups from a remote

location. Conducting focus groups on the Internet is cost-effective as it allows participants to remain in their own homes. These benefits are also true of telephone focus groups which are conducted using telephone conferencing and will be discussed in the following section.

2.2 Telephone conferencing

2.2.1 Practicalities

The facilities required for telephone conferencing are offered by a number of organisations such as Community Network, a British charity providing these services for other charities and non-profit-making organisations. Telephone conference participants do not require any special equipment, only an ordinary telephone. Participants can be telephoned by the telephone conference operator to connect them to the conference call. The booking organisation is charged for all the calls. Usually up to 10 people can participate in a single telephone conference and the session can be audiotaped by the telephone conference organisation with the permission of the participants. All conference calls are confidential to those participating.

Guidelines for facilitating telephone conferences have been devised by British Broadcasting Services and Community Network (1999). It is advisable for both the moderator and participants to be in a quiet location, free from distractions and interruptions. It may be a good idea to put participants at ease whilst they are waiting for the rest of the group to join the conference call by maintaining a general discussion. Participants could be asked initially to describe where they are sitting so that other group members can picture them and to say their first name every time before they speak so that everyone knows who is speaking. Silences during a telephone conference seem much longer than when having a face-to-face discussion. Although silences can be useful in telephone conference to give participants time to think, the moderator should break up a long silence (e.g. 5-10 seconds).

2.2.2 Benefits and limitations

Research has been conducted to investigate the benefits and limitations of telephone conferencing. Galinsky et al. (1997) conducted a questionnaire survey of 213 social work practitioners to investigate their experience and opinions of providing group services through telephone conferencing or computer technology.

Technology-based groups were seen to be more convenient, allow greater accessibility and anonymity than face-to-face groups. However, the limitations experienced were a lack of interpersonal cues (e.g. eye contact, facial expressions and body language), technical difficulties (e.g. delays, faults and participants' unease) and interference with the group dynamics (e.g. delayed communication, lack of bonding, distractions and interruptions). Problems moderating a telephone conference were also described including difficulties eliciting participation, dealing with silences and having less control over the discussion.

In order to minimise these potential problems, Galinsky et al. (1997) suggest: increasing cues (e.g. asking participants to identify themselves every time they contribute, encouraging them to clarify opinions, prompting them to convey emotions); technical difficulties need to be anticipated, minimised and efficiently resolved (e.g. moderators should be trained and practised, participants should be helped to feel at ease with the technology) and moderators may need to take a more active role in directing the discussion than they would in a face-to-face group.

2.2.3 Telephone support groups

Telephone conferencing has been used in a variety of settings which commonly include support groups. It is an “innovative means of offering health and mental health services” where there may be numerous barriers to participating in face-to-face groups (Galinsky et al., 1997).

Telephone groups are becoming a popular means of providing support for various groups of people including the elderly, individuals with HIV/AIDS and cancer patients.

Twenty-three elderly people with disabilities participated in a series of weekly telephone support groups over a 12-week period (Stewart et al., 2001b). Each group was jointly led by a health professional and peer. The groups were recorded, transcribed and qualitatively analysed. In addition, participants were also individually interviewed following the last group. The findings indicated that the groups had been effective in meeting needs for support, reducing loneliness and improving coping in this group of people.

Rounds et al. (1995) developed and evaluated a series of telephone support groups for 29 people with HIV disease. This intervention aimed to “increase self-efficacy, decrease social isolation and increase social support and enhance coping related to living with HIV disease”. Although not all of study aims were met, participants were very satisfied with the intervention and reported experiencing

substantial support and group bonding. Few problems in communicating in the telephone conference environment were identified.

A pilot study was conducted to evaluate a telephone support group intervention for male haemophiliacs with HIV/AIDS and family carers (Stewart et al., 2001a). Eleven participants completed a series of 12 weekly telephone support groups and were then individually interviewed about the intervention. The telephone support groups were facilitated by a mental health nurse and a peer, who were themselves interviewed after the intervention. Qualitative analysis revealed that although the intervention had helped to meet the support needs of participants, it also highlighted areas where the intervention could be improved.

Colón (1996) described a long-term series of telephone support groups to provide psychosocial support for 12 cancer patients who were unable to attend a face-to-face group. Wood et al. (1999) evaluated the impact of a series of four telephone support groups for cancer patients (who had completed their radiotherapy treatment but had not yet started follow-up appointments) on psychological distress. The results supported the value of telephone support groups in this group of patients and demonstrated that psychological distress had been alleviated in some, but not all participants.

2.3 Telephone focus groups

Telephone focus groups are described by Greenbaum (1998). They take place during a telephone conference call, where the moderator and participants can all remain in separate locations. The duration of a telephone focus group is usually one hour which is much less than the traditional face-to-face group. Telephone focus groups offer greater anonymity than any other form of focus group and are a cost-effective way of connecting people who live within a large radius.

As the telephone focus group is a relatively new methodology, references to it in the published literature are scarce. Ruef & Turnbull (2001) investigated the opinions of key stakeholders on information currently available to enhance quality of life in people with challenging behaviour using telephone focus groups and one-to-one interviews. Siripant et al. (2001) conducted face-to-face and telephone focus groups to gain the perspectives of nurse practitioners on issues regarding oral cancer. The results suggested future strategies to help reduce the number of deaths from oral cancer.

2.4 Rationale for using telephone focus groups to investigate living with an increased risk of breast cancer

Qualitative methodologies have been promoted as the best means of investigating an unknown area and generating hypotheses (Miles & Huberman, 1994). Of the variety of qualitative methodologies, focus groups are particularly suited for use in exploratory research. They are ideal for generating hypotheses that can subsequently be tested in further larger-scale research.

The focus group methodology offers particular advantages for exploring the long-term psychosocial effects of living with an increased risk of breast cancer. The focus group environment may enable participants to feel comfortable about sharing their experiences and they may consequently give more open responses. Interaction between group members and the moderator can enhance the data collected and may reveal unexpected but valuable issues. Participants may also benefit from taking part in a focus group as it may provide mutual support or may be empowering. Focus groups enable data on a range of experiences to be collected efficiently. They have previously been used effectively in women at increased risk of breast and ovarian cancer.

Morgan (1997) suggests that in order to decide in the simplest way if focus groups are the most appropriate methodology for a particular research topic, you should predict the ease with which the discussion among the participants would flow. If this simple rule is applied to test the suitability of using focus groups in the current work, it does seem likely that women who have been living with an increased risk of breast cancer over a number of years could share their experiences in some depth with others in the same situation.

Conducting focus groups via a telephone conferencing system would overcome the expense and inconvenience for participants who live within a large area of attending a face-to-face session whilst maintaining many of the benefits of the focus group methodology.

Chapter 3: Telephone Focus Group Study to Explore the Psychosocial Effects of Living with an Increased Risk of Breast Cancer *

3.1 Introduction

The clinical services offered to the majority of women estimated to be at increased risk of breast cancer are generally limited to annual breast cancer screening appointments. Most of these women are not eligible for genetic testing or prophylactic surgery. Women who are living with an increased risk of breast cancer face continuing multiple uncertainties regarding their own risk, the risk of family members and the effectiveness of breast cancer screening methods currently offered to them. Living with these multiple uncertainties and facing the prospect of years of clinical surveillance may have important consequences for an individual including psychological distress and adherence to breast cancer screening.

A review of the psychological literature (Chapter 1, Section 1.5, page 16) highlighted a lack of knowledge about the psychosocial consequences of living with an increased risk of breast cancer for the growing numbers of women who have been living with this risk a number of years. However, research has found evidence that a substantial proportion of women with a family history of breast cancer are experiencing significant levels of psychological distress up to 25 months following genetic risk counselling (e.g. Lloyd et al., 1996; Cull et al., 1999; Watson et al., 1999; Hopwood et al., 2001; Meiser et al., 2001b; Bish et al., 2002). There is a clear need to carry out similar research in the growing numbers of longer-term attendees of familial breast cancer clinics (i.e. those who have been living with an increased risk of breast cancer for over two years). In addition, there is limited understanding of the needs of these women in terms of information about issues related to their increased risk of breast cancer and psychosocial support to help them cope. Clinicians at the familial breast cancer clinic have expressed concerns that such needs are not likely to be met by the existing clinical service.

* Material from this chapter has been published (see Appendix I for a copy of the paper).

The initial study was of an exploratory nature to gain these women's perspectives of living with an increased risk of breast cancer and to identify any needs for information or psychosocial support that were not being met by the existing clinical service. Telephone focus groups were selected as the most appropriate methodology to conduct the study (Chapter 2, Section 2.4, page 50). The results of this preliminary study were intended to form the basis of subsequent studies.

3.2 Aims

This study aimed to explore the long-term psychosocial consequences for women of being informed about an increased risk of breast cancer in terms of:

- the effect on everyday life.
- the coping strategies used.
- unmet needs (information about breast cancer risk-related issues, psychosocial support) in terms of the current service at the familial breast cancer clinic.

3.3 Design

This study adopted the novel methodology of telephone focus groups, which uses the focus group methodology conducted via a telephone conferencing system. In addition, feedback from the telephone focus groups was collected by postal questionnaire.

3.4 Participant selection

Women with a family history of breast cancer in South East Scotland who had participated in psychosocial studies conducted several years previously (i.e. Cull et al., 1998; Cull et al., 1999) were listed on a database. Each participant was checked for her eligibility to participate in the study with a genetic breast care nurse, using her clinical database of attendees at the familial breast cancer clinic (Eligibility criteria are listed in Table 3.1). A sample of those meeting the study criteria was invited to participate (i.e. by selecting every third participant from an alphabetical list).

Table 3.1: Eligibility criteria for the telephone focus group study

Inclusion criteria:

- Current attendance at the Ardmillan Familial Breast Cancer Clinic.
- Has attended the Ardmillan Familial Breast Cancer Clinic for at least two years.

Exclusion criteria:

- A previous diagnosis of cancer.
- Has had prophylactic surgery.
- Has undergone genetic testing.
- Current participation in any other psychosocial research in relation to their family history of breast cancer.
- Current participation in the International Breast Cancer Intervention Study (IBIS), Magnetic Resonance Imaging (MRI) Trial or the Cancer Genetics in the Community Trial.
- Has participated in the pilot interviews prior to this study to develop the moderator guide.

3.5 Measures and instruments

3.5.1 Sociodemographic variables

Several sociodemographic variables were obtained from the database from which the participants were selected: age, number of years attending the familial breast cancer clinic, objective breast cancer risk, marital status, number of children and number of daughters.

3.5.2 Moderator guide

Twelve pilot interviews were conducted prior to this study with women at increased risk of breast cancer who were attending the familial breast cancer clinic for a routine breast cancer screening appointment. Data from these interviews were used to develop standard stimulus questions and probes which formed the main section of a semi-structured moderator guide (A copy of the moderator guide is in Appendix II, page 1). This consisted of:

- an introduction to:
 - welcome participants.

- set ground rules (e.g. participants identify themselves before speaking by their first name only).
- allow participants to introduce themselves to the group.
- stimulus questions and probes to ensure that each group discussed the following three main topics:
 - *effects* of living with an increased risk of breast cancer on everyday life (in terms of: the way they do things, the way they think, the way they feel and their relationships with other people in their family).
 - *coping* with an increased risk of breast cancer (in terms of: what has helped them to cope and has anything been difficult to cope with).
 - unmet needs in terms of the current *service* (in terms of: do they have any needs for additional services that are currently not being met and how should these services best be provided).
- a conclusion to:
 - thank participants.
 - allow participants to say goodbye to the group.

3.5.3 Feedback questionnaire

A brief study-specific questionnaire was developed to: clarify some of the opinions that were raised in the telephone focus groups about *living with an increased risk of breast cancer* and *service issues*; provide feedback on *participating in a telephone focus group*; collect information about participants concerning *genetic testing*. The latter set of questions was included as it became apparent during the first telephone focus group that one of the participants had undergone genetic testing. Therefore, the responses to these questions provided additional information about genetic testing to supplement that obtained from the clinical records (A copy of the feedback questionnaire is in Appendix II, page 6). The questionnaire consisted of these four main sections:

1. **Living with an increased risk of breast cancer:** Eight items concerning effects on everyday life (e.g. How much has knowing about an increased risk of breast cancer in your family changed the way you generally feel?) and difficulties coping (e.g. Have you found it difficult to cope with knowing that there is an increased risk of breast cancer in your family?). Responses were on a 4-point Likert scale (1 = not at all, 2 = a little, 3 = quite a bit, 4 = very much) (except for one item where responses were open-ended).

2. **Service issues:** Ten items clarified unmet needs in terms of the current service. Participants were asked to if they would like to be provided with: updated information (and were asked to rank in order of preference a list of eight topics related to familial risk of breast cancer), things to help them cope with any stress they may be experiencing, the opportunity to meet up with other women in the same situation, something for other family members and the opportunity to have any questions answered outside of the clinic time. Responses were as yes/no choice. Participants were asked to indicate their preferences for the format of these services (e.g. written materials or personal contact?) by endorsing the appropriate item. They were also asked about their access to the Internet and e-mail and if this would be a convenient way for them to receive information (responses were as yes/no choices).
3. **Participating in a telephone focus group:** Seven items provided feedback on the acceptability of the telephone focus group methodology in terms of: the ease of making their opinions known, if they thought the leader handled the discussion well, their comfort about sharing their experiences in the group, if they found participating helpful and their overall experience of the telephone focus group. Responses were on a 4-point Likert scale, which varied between items (e.g. from 1 = not at all to 4 = very much; from 1 = poor to 4 = excellent). Participants were also asked if they had used telephone conferencing before, how many times and for what purpose (i.e. job or home life).
4. **Genetic testing:** Four items identified if any participants had been through the genetic testing process in terms of: if a faulty gene had been identified in their family, if they had been tested for this faulty gene, if they had received the results of this test and if they were found to carry the faulty gene. Responses were as a yes/no/not applicable choice.

3.6 Procedure

The regional ethics committee approved the study. Each woman was sent a letter asking if they would be willing to take part in a telephone discussion group to share their experiences of living with an increased risk of breast cancer. They were also sent an information sheet, two consent forms (one was specifically for consenting to being audiotaped), a response sheet to indicate preferred days/times within a two-week period and a freepost envelope. The General Practitioners of all women consenting to participate were notified by letter.

Those women who consented were allocated to a telephone focus group at a time to suit their convenience and were sent a letter confirming the specific date and time of their group. This letter also provided some brief instructions about participating and notified them that they would be telephoned several days before their scheduled group. During this short phone call, the moderator followed prepared guidelines (A copy of the guidelines is in Appendix II, page 13) to ensure that the women were still able to participate, to give them an opportunity to familiarise themselves with the moderator's voice, to be introduced to the structure of the focus group and to allow them to ask any questions.

The telephone focus groups were conducted following published guidelines for focus groups (Greenbaum, 1998; Tobin, 1996; Vaughn et al., 1996), which were modified for use with the telephone conferencing system. The moderator who conducted the telephone focus groups (S.A) received prior training in telephone conferencing (organised by British Broadcasting Services and Community Network) and conducted several practice telephone focus groups with colleagues and postgraduate students recruited from a health psychology e-mail network (Appleton, 2000).

The telephone conferencing system was operated by Community Network (a centre for voluntary sector telephone conferencing). At the allotted time of each telephone focus group session, the participants were telephoned by the Community Network operator to connect them to the conference call (i.e. the participants were not charged for the call), always beginning with the moderator. When all participants had been connected, the moderator facilitated the group using the moderator guide. All groups had the same moderator (S.A), lasted for no longer than one hour and were audiotaped by Community Network. A protocol was in place in the event that any participant became distressed during the session. Immediately after each group, the moderator made a summary of the discussion. These summaries were compared to the final outcome of the qualitative analysis as an indication of the reliability of these results (see Table 3.2: Stage 2, Step 4).

The participants were sent the feedback questionnaire a few days after their group.

3.7 Analysis

The distribution of all continuous sociodemographic variables was assessed to determine their parametric or non-parametric nature. The appropriate descriptive statistics were generated to describe the study participants. Differences between participants and non-participants on the sociodemographic variables were assessed by independent samples t-tests (2-tailed), Mann-Whitney tests, chi-square tests or Fisher's exact tests. Marital status was recoded as a dichotomous variable for analysis using the Fisher's exact test (i.e. married or cohabiting vs. not married or cohabiting). A significance level of 0.05 was used throughout. The data were analysed using SPSS for Windows version 10.00 (1999).

The audiotapes of the telephone focus groups were transcribed verbatim before undergoing a qualitative analysis. They were analysed independently by three researchers using a modified version of published guidelines for analysing focus group data (Vaughn et al., 1996). The process by which quotes, themes and key issues were identified in two main stages is explained in Table 3.2 . A rigorous record of the whole analysis process was kept including all independent analyses and the result of all negotiations. Although the majority of the analysis process was completed by hand, WORD macros were created to allow the text to be automatically copied from the transcripts into new files.

The feedback questionnaire was quantitatively analysed in terms of frequencies and percentages.

Table 3.2: Qualitative analysis of the telephone focus group data

Stage 1.

For each of the three research areas separately (i.e. Effect, Coping, Services):

1. Informative quotes identified (SA, AF, GR)*.
2. Consensus achieved on a final list of quotes (SA, AF, GR).
3. Themes developed from the quotes (SA).
4. Reliability of themes assessed. Quotes independently assigned to themes (AF, GR). Inter-rater reliability between pairs of the three raters calculated using Cohen's Kappa.
5. Discrepancies negotiated to achieve consensus on a final set of themes with supporting quotes (SA, AF, GR).

Stage 2.

Completed by SA only:

1. Themes and supporting quotes from each of the three research areas collapsed to form one dataset of 44 themes and 756 quotes.
2. Extraction of 29 themes supported by quotes from at least 3/7 transcripts.
3. Related themes grouped to form six key issues.
4. Reliability of six key issues assessed by comparing to the moderator's summaries of the telephone focus groups.

* initials refer to the named authors (for a copy of the published paper see Appendix I).

3.8 Results

3.8.1 Participants

Of the 214 women listed on the database of women with a family history of breast cancer, 155 were eligible to participate in the study (59 women did not meet the study criteria). From these 155 women, a sample of 52 was initially identified by selecting every third woman (from a list arranged alphabetically by surname). The clinical case notes for two women could not be located to gain their contact details. Therefore, 50 women were invited to participate in the study. Twenty-six women responded of whom 22 were willing to participate. Two women were not willing for personal reasons (i.e. her husband had just been made redundant; she felt that she currently had too much going on in her life) and two were not available as they would be on holiday over the scheduled study period. The 24 women who did not respond to the initial invitation were not contacted for a second time. Due to the low

initial response rate, a second group of 30 women was identified two weeks later by randomly sampling the remaining 103 potential participants. Twenty of these women were invited to participate (the clinic case notes for 10 women could not be located to gain their contact details). Seven women replied to the invitation of whom six were willing to participate and one woman was not willing for personal reasons (i.e. she felt participation might unbalance her strategies for coping with her increased risk). The 13 women who did not respond were not contacted for a second time.

Therefore, 28 women in total consented to participate in the study and 25 women actually took part. The availability of one woman could not be accommodated into the focus group schedule (she was only available for 2 hours during the 2 week study period) and two women pulled out of their telephone focus group at the last minute for personal reasons (i.e. her mother had recently received a diagnosis of recurrent breast cancer; she was unavailable at the last minute). There were no significant differences between the participants ($n = 25$) and non-participants ($n = 45$) in terms of their age, number of years attending the familial breast cancer clinic, objective breast cancer risk, marital status, number of children and number of daughters.

Seven telephone focus groups were conducted over a period of nine days of which five groups had four participants and the remaining two groups comprised three and two participants. Six of the groups took place on weekdays and one was on a Saturday. Four of the groups took place in the morning and five were conducted in the evening.

Participants ranged in age from 27–51 years (mean = 41.3, SD = 5.9). They had been attending the clinic for between 2.5 – 6.5 years (mean = 5.2, SD = 1.2). Their objective lifetime risk of breast cancer which had been provided during genetic risk counselling ranged from 20-40% (mean = 27%, SD = 7.1). The majority were married or co-habiting (80%), had children (76%) and of those that had children, 63% had at least one daughter.

3.8.2 Qualitative analysis

The results are presented in two main sections: key issues and additional issues. The thematic structure of the six key issues is shown in Table 3.3.

Table 3.3: Structure of the key issues

<i>Key issue</i>	<i>Theme</i>	<i>Number of supporting quotes</i>	<i>Number of transcripts containing the theme (max. 7)</i>
Psychological adaptation	• Chronic emotions and cognitions	75	7
	• Acute emotions and cognitions	31	7
	• Sensitivity to breast cancer cues	27	7
	• Time and age	23	6
	• Focusing on the present	16	5
	• Avoidance	18	6
	• Positive thinking	7	5
	• Decisions and plans	22	6
	• Reassessment of life and priorities	24	7
Behavioural adaptation	• General health behaviours	25	7
	• Control	6	4
	• Breast Self-Examination	12	6
Family issues	• Family	52	7
	• Emotional support	14	6
	• Breast cancer survivors	13	4
	• Children	35	7
Clinical surveillance	• Frequency of clinic appointments	12	3
	• Duration of clinic appointments	7	3
	• Continuous support	5	3
	• Clinical services	21	6
	• Specialist care	30	7
	• Reassurance and security	36	7
Provision of information	• Knowledge	22	7
	• Getting a balance	6	3
	• Type of information	37	7
	• Method of information presentation	28	6
	• Family involvement	14	6
	• Immediate telephone contact	17	6
Peer support	• Support from other women in the same situation	17	5

Inter-rater agreement between pairs of the three raters to assess the reliability of the themes was good (Kappa = 0.61 - 0.79) according to published guidelines (i.e. Altman, 1991). The six key issues reflected the main issues included in the moderator's summaries of the telephone focus groups.

The additional issues consisted of topics arising in the focus groups that were not included in the qualitative analysis. Nevertheless, these topics had some relevance to the aims of the study and therefore supplement the information provided in the key issues.

3.8.3 Key issues

3.8.3a *Psychological adaptation*

The themes associated with psychological adaptation to knowing about an increased risk of breast cancer in the family were: chronic emotions and cognitions; acute emotions and cognitions; sensitivity to breast cancer cues; time and age; focusing on the present; avoidance; positive thinking; decisions and plans; reassessment of life and priorities (quotes from the telephone focus groups to support the themes associated with psychological adaptation are listed in Table 3.4).

Table 3.4: Psychological adaptation

Chronic emotions and cognitions:

"I think maybe the hardest thing I've had to do is to accept that this (breast cancer) will be an ongoing fear, there will never come a time in my life when I will know, at least with current medicine as it is, there probably will never come a time when I will think, well this is something I won't get".

Acute emotions and cognitions:

"I had a biopsy recently as well and it nearly put me through the couch when they decided they were going to do it...I was amazed at the feelings that I had when they said, you know, 'we need to test this here' and the reaction was really quite strong".

Sensitivity to breast cancer cues:

"I would describe myself as being a bit of cancer phobe.... My reaction tends to be if somebody's ill, my first reaction is, 'Oh God it's cancer' or if there's something wrong with me or people close to me like my partner or my son, my first reaction is, 'I hope it's not cancer'.

Time and age: (changes in emotions or cognitions over time or with age)

"...it's when the time of the year comes, May/June period, that's when it actually, you're facing it front on and that for me is the hardest thing to cope with, waiting for the mammogram, waiting for the results and wondering if it's positive, how you're going to cope with it and then you get the letter through to say it's negative and then you sigh another sigh of relief for another year".

Focusing on the present:

"I tend to get on with whatever's going on in my life at the moment and deal with whatever happens when it does".

Avoidance: (of breast cancer cues)

"I will avoid it (breast cancer), watching it on the television. I won't avoid talking to anybody about it. I won't watch it. I won't confront myself with it on a continual basis from the television or anything like that".

Positive thinking:

"I'm an optimist by nature I suppose, I'm not a worrier and then I have good health in general so I sort of feel ...that I should be able to cope with this and my overall robust immune system and it will minimise the risk and that's generally the sort of attitude I've taken and these things all help".

Decisions and plans:

"I haven't had to cope with it but always at the back of my mind is the question - what would I do if it was suggested I underwent, say, a preventative mastectomy? If I was asked or that was suggested to me that would be very, very difficult - what do I do? Obviously I haven't had to face that yet but that would be a very difficult thing, to do something to prevent getting the disease".

Reassessment of life and priorities:

“...every time I get the all clear from a mammogram or from a physical examination by GP, it feels like, a sort of, well, you know, new lease of life isn’t quite the right expression but I think, well I’m still OK and I am immensely thankful, so in terms of sort of valuing life and current state of health, it makes me very appreciative every time I feel I’m still OK”.

A common way of adjusting to knowing about an increased risk in the long term was described as “taking one day at a time”. Women discussing their *chronic emotions and cognitions* commonly felt there was nothing to be gained from considering uncertain future scenarios. Other women described varying levels of breast cancer worry from mild or subconscious to severe worry and intrusive thoughts.

Acute emotional and cognitive responses such as anxiety, depression, shock, surprise and feelings of neglect were described as being triggered by risk related events such as being initially informed about their increased risk (by a health professional), receiving an appointment letter, waiting for an overdue appointment, having a mammography or biopsy and receiving the results (even if they showed no signs of breast cancer).

Some women described a heightened *sensitivity to breast cancer cues* such as changes in their breasts, media reports about breast cancer and illness in the family. One woman described herself as a “cancer phobe” as her first reaction to any illness in her family tended to be “I hope it’s not cancer”. This heightened sensitivity to breast cancer cues either prompted increased vigilance through breast self-examination, greater interest in media reports, increased anxiety or the avoidance of these cues.

Emotional and cognitive fluctuations over *time* were described, particularly in relation to the annual screening cycle. Breast cancer awareness, fear or worry commonly increased as the women approached the *age* at which an affected relative had been diagnosed with breast cancer: an effect described as “a psychological cut-off date”, like “a time bomb” or “a big shadow”. Conversely, once this age had been passed, any increase in anxiety levels gradually subsided.

The women described a variety of cognitive strategies for coping with the knowledge of their increased risk such as *focusing on the present*, *avoiding*

potentially worrying breast cancer cues and *thinking positively* about the situation by adopting an optimistic attitude about the future.

Although knowing about their increased risk had generally not affected the women’s *decision-making* or *planning* for the future, anxiety was expressed about having to make important choices in the future regarding genetic testing or preventative surgery.

Knowing about their increased risk of breast cancer had prompted several women to *reassess their lives and priorities* in positive ways such as living life to the full and prioritising their health.

3.8.3b Behavioural adaptation

There were three themes that were related to behavioural adaptation. These were general health behaviours, control and breast self-examination (quotes from the telephone focus groups to support the themes associated with behavioural adaptation are listed in Table 3.5).

Table 3.5: Behavioural adaptation

<p><i>General health behaviours:</i></p> <p>“I think I’m quite careful most of the time about doing anything that I think I can do to decrease my chances of getting breast cancer in terms of eating quite healthily and making sure I take quite a lot of exercise. Also being aware of stress levels, not necessarily doing relaxation exercises but being aware when I am stressed and always sort of thinking I should do more relaxation techniques, the things that I feel I can do to, if you like, take charge of my health as much as I can”.</p>
<p><i>Control:</i></p> <p>“...all these things help you to feel you are in control of the situation rather than the situation is in control of your life so I think it is very important to do things, positive things, to make you feel you are doing all you can, you know, not to have it (breast cancer)”.</p>
<p><i>Breast self-examination:</i></p> <p>“I feel that going to the clinic has been the most positive thing that’s ever happened and just while I remember it, because I go to the clinic...I don’t religiously check myself for lumps every month but that is the one trigger, cause I’m terribly forgetful but that triggers my memory every so often - ‘all right you never did it last month but you better do it this month’ - so it’s making me go through something that I might possibly not bother doing”.</p>

Although some women were already maintaining a healthy lifestyle, for many knowing about their increased risk had prompted them to adopt new *general health behaviours* such as a healthy diet, exercise, stopping smoking, use of natural remedies and stress management

These women described how adopting these behaviours had helped them to gain some *control* over their increased risk. Others described making a conscious effort to pass these healthy attitudes on to other family members, especially their children.

For many women, knowing about their increased risk and attending the clinic prompted increased vigilance about performing *breast self-examination*. However, one woman chose not to perform breast self-examination in order to avoid exacerbating her existing anxieties.

3.8.3c Family issues

The themes associated with family issues were family, emotional support, breast cancer survivors and children (quotes from the telephone focus groups to support the themes associated with family issues are listed in Table 3.6).

Table 3.6: Family issues

<p><i>Family:</i> “Having an increased risk of breast cancer doesn’t (just) affect you, it affects everybody around you as well”.</p> <p><i>Emotional support:</i> “...with having two sisters we discuss it (breast cancer risk) an awful lot which I think helps enormously because we are all in the same position and I think we get a lot of strength from the fact that we all discuss it and we are all very close”.</p> <p><i>Breast cancer survivors:</i> “I’m lucky in the fact as well that I have you know, more surviving relatives that have had breast cancer and are fine and that’s a big inspiration you know, you think well it’s beatable it’s not a death sentence”.</p> <p><i>Children:</i> “...I can cope with sort of having the gene or whatever but it suddenly dawned on me about my own two daughters and I think as time’s gone on, I felt, God, I hope not. I can cope with it myself but I wonder about my children, maybe that’s over the years I’ve thought that now”.</p>

Some women openly discussed their increased risk with other *family* members. This commonly resulted in closer relationships with mothers or sisters who had breast cancer or who were also at increased risk. Partners were often described as lacking insight into the women's feelings, which limited the discussion and the support provided. For these women, their increased risk was very much a family affair, involving family members in visits to the clinic and raising their relatives' awareness of cancer. Women, in families where a close relative was suffering from breast cancer or where discussion about breast cancer was generally avoided, described their reluctance to discuss their increased risk with family members. Other women regarded their increased risk very much as their own problem and thought it unnecessary to involve others at this stage.

Two main sources of *emotional support* were described by the women: family and friends, particularly mothers and sisters, and professionals such as the clinic staff and counsellors. *Breast cancer survivors*, who tended to be the women's mothers, were also an important source of strength and support.

The women commonly expressed concerns about the implications of their increased risk for their *children*, especially their daughters. Women with young children were predominantly worried about their children's ability to cope if they developed breast cancer. This reflected their own experience of losing their mothers at a very young age. Women with older children described their growing concerns regarding their children's own inherited risk.

3.8.3d Clinical surveillance

A number of themes were discussed that related to clinical surveillance. These were frequency of clinic appointments, duration of clinic appointments, continuous support, clinical services, specialist care and reassurance and security (quotes from the telephone focus groups to support the themes associated with clinical surveillance are listed in Table 3.7).

Table 3.7: Clinical surveillance

Frequency of clinic appointments:

“...what was an annual visit at the moment seems to be about 18 months but I’m not sure if it’s going to be longer and I don’t have particular difficulty if it ends up that the clinic, for me, ends up being every two years but I would rather know that than at the moment think that I’m six months late and that apparently I’m on an emergency cancellation list kind of thing. I think I would much rather know, well look, we either provide the resources to ensure that we can have it annually. If really it’s not necessary annually then let’s make it every two years but let’s, you know, I’d rather not be thinking well perhaps I’m six months late, I’d rather think I’ve got six months to go to the next one”.

Duration of clinic appointments:

“...when I did get my appointment I was in and out I mean very, very quickly without time to discuss anything...I almost felt last time that I was inconveniencing them, although they never purposely make me feel that way, I felt that I was taking up time”.

Continuous support:

“I sometimes think it’s true what they say, I mean an hour a year is better than nothing, but what happens for the rest of the year. You’re out there on your own”.

Clinical services:

“I’ve been going to the clinic for about five years and straight from the word go I was offered a mammogram on an annual basis and I have to say that concerned me because I don’t know that I really want this x-ray every year because that could put me at risk, you know, that could may be prompt something to grow that’s just maybe not going to if I hadn’t had the x-ray”.

Specialist care:

“The most positive, the turning point I felt, was when I was referred to the breast clinic at Ardmillan ...because not all the medical profession can deal with people who have a high risk and they don’t always have the knowledge, the specialist knowledge. Whereas when you go to Ardmillan, I do feel that at least you feel once a year you are being checked over and you are in the right place and you have contact with them and that makes a big difference”.

Reassurance and security:

“I think the fact that knowing that you can attend the clinic once a year really makes quite a difference to stopping you from worrying and having the same sort of apprehension, if you like, in the back of your mind, because you always know that although you may check yourself there is always someone else there, you know, to do the extra check for you, just to make doubly certain”.

Many women described how their annual *clinic appointments* had become less *frequent* with a shorter *duration*. Some women were concerned that these changes in service provision added to existing uncertainties and could be damaging to their health. Several women emphasised a need for some alternative form of *continuous support* to compensate for the existing clinical pressures.

Although several women felt very closely monitored by the current *clinical services*, some women described their concerns about the possible side effects of mammography together with reservations about participating in research trials.

Many women expressed how privileged they felt to be receiving such *specialist care* and how confident they felt both with the expertise of the staff and the equipment. Much importance was placed on the clinical service, in terms of alleviating any anxieties, providing the opportunity for the early detection of breast cancer and informing them of any significant medical advances.

Feelings of *reassurance* both from the clinic and their own general practitioner were frequently voiced, particularly when the women found breast-self examination difficult. They also found that the clinic provided them with a sense of *security* as they were always aware that help was just a phone call away. Many women found this a comfort and an aid to coping with their increased risk.

3.8.3e Provision of information

Themes relating to the provision of information were knowledge, getting a balance, type of information, method of information presentation, family involvement and immediate telephone contact (quotes from the telephone focus groups to support the themes associated with the provision of information are listed in Table 3.8).

Table 3.8: Provision of information

Knowledge:

"I think that knowledge and information, the more knowledge and information you have, the easier it is to cope with things and the more it helps you".

Getting a balance:

"I think it's dangerous. I think people can dwell on things that aren't there and are maybe never going to happen. I think it's very hard to get the balance right and probably very hard when you're trying to provide a service as well".

Type of information:

"I think information of the right sort, coming from the right people, would make quite a great deal of difference to know that what you were getting was, you know, probably not what you were reading in the daily papers which you can never believe or not".

Method of information presentation:

"I think people these days, they like to be informed, they want to know what's going on and what research is showing. But, you know, to have it explained in a way they can grasp and understand and I think that's a problem with being sent stuff in the post, if people don't understand it, there's nobody to ask or to question. I think that would be the beauty of having an informal type of meeting where people could maybe get the chance to talk to people after the presentations or whatever. I think that would be invaluable".

Family involvement:

"I think that it would probably be a good idea for partners to attend (a meeting) because it might help them to understand what it feels like for women to be under this sort of increased risk. I think that some partners kind of shut themselves off from it and don't take any notice of it. It might help their understanding. Yes, I think for partners, it would be good for them to attend".

Immediate telephone contact:

"I also think that possibly a telephone help-line maybe a good idea so that as someone else mentioned had quite problem getting through. I did as well at one point trying to get to speak to someone, for something I wanted to ask about and I really had quite a struggle to get to actually speak to someone. I think if there was a telephone help-line set up, possibly even may be just certain hours throughout the day not necessarily the whole time, that someone could just pick up a telephone, rather than having to wait on their appointment every year. I think that would be quite helpful".

Discussion about the role of *knowledge* in coping with an increased risk uncovered contrasting experiences. Many women found that being informed about breast cancer-related issues had helped them to cope by aiding their decision-making

and decreasing anxiety. In contrast, other women felt that this sort of information often added to existing concerns. Several women felt that undergoing genetic testing to allow them to know whether or not they were carrying a breast cancer gene mutation would certainly help them to cope by decreasing some of the uncertainty of developing breast cancer. Some women suggested it was about *getting a balance* between being informed and increasing worry, but this was often difficult to maintain.

The women commonly expressed a need for specific *types of information*, particularly up-to-date, professionally approved, detailed information on a variety of topics including the clinical services available (particularly genetic testing), scientific research (concerning breast cancer treatments, current trials and genetics), preventative measures (such as diet), hormone replacement therapy, the oral contraceptive pill and stress management.

A variety of opinions were expressed about the best *methods of presenting this information*. There was a widespread positive response to the idea of *presenting this information* via an organised face-to-face meeting which would provide the women with a direct opportunity to ask questions.

Written information was seen to be very convenient and a valuable reference, but generally supplementary to gaining information on a face-to-face basis. Other suggestions to be kept informed included a newsletter, web site and Internet news group.

Discussion about *involving the family* uncovered some differences of opinion about who should attend an organised meeting. Several women thought that all family members should attend, others felt that it would only be beneficial for their partners and some expressed their reluctance to attend if other family members were invited. These women preferred to relay any relevant information to their families.

Many women described problems contacting the clinic and would welcome some form of *immediate telephone contact*, such as a telephone help-line, for gaining instant advice from a specialist clinician. Several women felt that access to such a service would provide them with an extra source of reassurance.

3.8.3f Peer support

Table summarises the theme relating to peer support, which was *support from other women in the same situation* (a quote from the telephone focus groups to support the theme associated with peer support is in Table 3.9).

Table 3.9: Peer support

Support from other women in the same situation:

“...if I was to go to some sort of group meeting where people were in a similar position to me, I suspect that’s the group where I might feel comfortable and be able to say, ‘Look maybe I am worried’, where I might not say that at home because if I have had somebody who’s had breast cancer...I certainly am the one being terribly positive with her (my mother) and therefore would not want to take her along and hear me say, ‘maybe I have been worried’, so I’d quite like I think the idea of the empathy with a group with similar circumstances”.

Many women suggested that it would be beneficial to have some form of contact with *other women in the same situation* either face-to-face, by telephone or via an Internet chat room. They felt that it would be helpful to share their experiences in a support group setting or as part of a social event. Several women thought that they would feel sufficiently comfortable in a group of woman in the same situation to be able to openly voice their concerns. One woman, who had a positive view of her increased risk, felt that she could provide support to other women, who perhaps were finding it difficult to cope.

3.8.4 Additional issues

There were a number of additional issues that were discussed in the telephone focus groups that were not included in the qualitative analysis, but have some relevance to the aims of the study.

Firstly, from the large amount of discussion concerning genetic testing for breast cancer, it was apparent that a lack of knowledge had resulted in confusion for some of these women. Several of the women’s relatives had given blood for genetic testing several years previously, but the family had not received any updated information about this process since that time. Some of these women felt that this information was purposely being kept from them and several even thought that the psychological questionnaires they were completing in conjunction with their annual appointments at the clinic, were in fact screening tools to assess whether or not they could cope with this genetic information.

Secondly, many women highlighted the inconsistent and unreliable nature of a large proportion of media reports about breast cancer issues such as the sensitivity of screening, possible risks associated with the pill and preventative dietary factors.

They found these conflicting reports very unhelpful and in some cases, anxiety provoking.

Thirdly, several women expressed their lack of confidence both in the sensitivity of mammography and the effectiveness of carrying out breast self-examination.

Fourthly, a number of women expressed a strong interest in actively helping to support the funding of the clinic in any way that they could.

Lastly, one woman described the reluctance of health professionals outside of the familial breast cancer clinic to give her advice about a possible breast cancer symptom. Although she tried to seek immediate advice from an alternative source, she was nevertheless referred back to the clinic to wait for an appointment.

3.8.5 Feedback questionnaire

All 25 participants returned completed feedback questionnaires.

3.8.5a Living with an increased risk of breast cancer

The majority of participants reported that knowing about an increased risk of breast cancer in their family had changed their everyday lives in terms of: the way they did things (*a little*: n = 17, 68%; *quite a bit*: n = 3, 12%; *very much*: n = 1, 4%), the way they thought about their life in general (*a little*: n = 15, 60%; *quite a bit*: n = 5, 20%; *very much*: n = 2, 8%), the way they generally felt (*a little*: n = 10, 40%; *quite a bit*: n = 6, 24%) and their relationships with other people in their family (*a little*: n = 11, 44%; *quite a bit*: n = 4, 16%; *very much*: n = 1, 4%).

Two questions asked participants about the extent to which knowing about their increased risk had affected their lives in positive ways (e.g. encouraging them to maintain a healthy lifestyle) or negative ways (e.g. causing them worry). With respect to positive effects, 19 participants (76%) reported *not at all/a little* and six (24%) reported *quite a bit/very much*. With respect to negative effects, 11 participants (44%) reported *not at all*, 12 (48%) reported *a little* and two (8%) reported *quite a bit*. No participants rated the negative effects as *very much*.

More than half of the participants had found it *a little* or *quite a bit* difficult to cope with the knowledge of their increased risk (n = 14, 56%). Things that were particularly difficult to cope with included concerns about their children's own risk of developing breast cancer, the constant fear of a breast cancer diagnosis, finding a lump in the breast, approaching the age when their mother had died of breast cancer

and the decreasing frequency of routine appointments at the familial breast cancer clinic.

3.8.5b Service issues

All participants reported that they would like to be provided with updated information on a variety of topics related to familial risk of breast cancer. Of the 20 women (80%) who listed the given topics of information in order of preference as requested, half ranked “current breast cancer research” as the most important topic, a quarter thought that information about “breast cancer screening” was the most important topic and for the remainder of participants other topics were their first choice (i.e. breast cancer treatment: $n = 2$, 10%; maintaining a healthy lifestyle: $n = 2$, 10%; genetic testing: $n = 1$, 5%).

The majority of participants indicated they would like information on stress management strategies ($n = 19$, 76%), the opportunity to meet up with other women in the same situation ($n = 22$, 88%) and the opportunity to have any questions answered outside of the clinic time ($n = 23$, 92%). Approximately half of the participants ($n = 12$, 48%) stated they would like to be provided with a service for other family members. With respect to the format of any additional services, 56% of participants ($n = 14$) indicated a general preference for written materials rather than personal contact, 60% ($n = 15$) preferred organised meetings rather than one-to-one sessions and 55% ($n = 14$) preferred face-to-face rather than telephone contact. Of the 10 participants (40%) who had access to the Internet and e-mail facilities, nine indicated that this would be a convenient way to send or give them access to information on topics related to familial risk of breast cancer.

3.8.5c Participating in a telephone focus group

The vast majority of participants had found it easy to make their opinions known during the telephone focus group (a little: $n = 3$, 12%; quite a bit: $n = 12$, 48%; very much: $n = 9$, 36%). All participants thought that the leader handled the discussion well (quite a bit: $n = 6$, 24%; very much: $n = 19$, 76%). Only one woman did not feel comfortable about sharing her experiences in a telephone focus group. Most participants had found it helpful to share their experiences with women in the same situation (a little: $n = 4$, 16%; quite a bit: $n = 6$, 24%; very much: $n = 14$, 56%). 84% of participants ($n = 21$) rated their general experience of taking part in a telephone focus group as *good* or *excellent*.

For nearly all of the participants (n = 23, 92%), this was the first time that they had taken part in a telephone conference call. The remaining two women often used telephone conferencing at work.

3.8.5d Genetic testing

Two participants reported that a faulty breast cancer gene had been identified in their family. Although both of these women stated that they had been tested for this faulty gene, only one woman had already received the test results and was found to be carrying the faulty gene.

3.9 Discussion

The telephone focus group methodology used in this study provided a rich source of information about the psychosocial consequences of living with an increased risk of breast cancer. As the information gained from later focus groups began to reiterate that collected from earlier groups, it encouraged us to believe that we had elicited the full range of issues for these women. The qualitative data were supported by the quantitative results of the feedback questionnaire.

3.9.1 Participants

The low response (47%) and participation (36%) rates were disappointing. This may in part be explained by the practical difficulties of gaining accurate contact information for women who only attend the clinic on an annual basis and the relatively short time frame offered for reply and participation. Scepticism among the women about the use of such a novel methodology may also have acted as a barrier towards participation. Therefore, the 25 participants may not be representative of the other 45 women invited to participate. Although these two groups did not differ significantly on the six demographic measures assessed, the participants may be biased in terms of the coping strategies they used (e.g. the invitation to participate may act as a breast cancer cue, stimulating an avoidant response) and may be unrepresentative in terms of psychological distress (e.g. highly distressed individuals may not have responded to the invitation). However, the aim of exploratory focus group research is not to generalise the findings to a larger sample, but to represent a range of participant views (Vaughn et al., 1996). The data collected did encompass a

wide range of opinions and experiences indicating that they are likely to reflect the important issues in this group. In any case, the intention was to test out the representativeness of the issues identified in a larger sample of women using more conventional questionnaire methodology.

3.9.2 Telephone focus group methodology

The use of telephone conferencing methods to conduct focus groups was a novel approach to research in this area. The methodology was shown to be a very useful and convenient means of accessing a wide range of experiences. With thorough preparation of the moderator guide and training in facilitating telephone conferences, the groups were relatively easy to organise and conduct. They only required an hour of the participants' time in the convenience of their own homes, which was important since many of the participants led busy lives. The groups were very cost-effective to run in comparison with the likely costs of conducting a face-to-face group (i.e. hiring a location, providing refreshments and covering participants' travel expenses). For example, in 1999 the total cost of running and recording a one-hour telephone focus group on a weekday evening for five people (including the moderator) was £28. The groups could have been made more cost-effective by including more participants in each group. However, following a review of the literature on focus group size and training in conducting telephone conferences, it was considered that four participants should be the maximum number per group for this study.

Participant feedback about the telephone focus groups was extremely positive. Any initial scepticism among participants was quickly dispelled as the anonymity of the telephone conferencing system made them feel less inhibited about sharing their experiences. No participants became distressed during their group or deliberately left the session before it had finished. Many participants expressed how beneficial they found this experience and were keen to participate again or follow up the group with a face-to-face meeting. There was also evidence that some women had started to "bond" with other members of the group despite the lack of face-to-face contact: as one woman commented, "I enjoyed the experience and even felt momentarily 'bereft' when I said goodbye to the other participants".

3.9.3 What are the psychosocial effects of living with an increased risk of breast cancer on everyday life?

This study provided an important insight into the women's experience of the long-term psychosocial effects of knowing about their increased risk of breast cancer on their everyday life.

Firstly, there was wide variation in the levels of anxiety and distress that these women described experiencing in the years since they first attended the clinic. A few participants reported experiencing severe worry and intrusive thoughts about breast cancer on a daily basis. There is a clear need to assess both the prevalence and type of psychological morbidity (e.g. general psychological distress, breast cancer-specific distress) in women who have been living with an increased breast cancer for a number of years and who are receiving appropriate clinical surveillance. This would enable interventions that aim to prevent or reduce psychological distress to be developed and targeted appropriately.

Secondly, anxiety and distress were often described as fluctuating over time in response to breast cancer-related cues such as approaching the time of a clinic appointment. Previous research provides evidence that levels of acute psychological distress in women with a family history of breast cancer are high immediately prior to routine mammography and are lowered after receiving normal results (Valdimarsdottir et al., 1995). Our findings suggest that the impact of such cues may be related to the individual's level of chronic anxiety or distress such that in chronically distressed individuals breast cancer cues further elevate their consistently high levels of distress. The possible relationship between chronic distress and a heightened sensitivity to breast cancer cues requires further investigation in a larger sample of women at increased risk of breast cancer.

3.9.4 What sorts of coping strategies are being used by women living with an increased risk of breast cancer?

There was evidence that the women in this study drew on a number of important internal and external coping resources including positive cognitions, knowledge about breast cancer-related issues, clinical surveillance and family members. Of the range of cognitive and behavioural coping strategies that were described, particular strategies such as cognitive avoidance were described as minimising anxiety and distress over time which may suggest that they have an adaptive role in the long-term. Behavioural coping strategies such as excessive

reassurance seeking were used in times of acute anxiety and distress. The use of behavioural coping strategies associated with adopting a healthy lifestyle was seen to be adaptive by promoting a degree of perceived control over a woman's increased risk. The findings of this study then suggest the incidental benefits that could accumulate by including a general health behaviour component as part of an educational intervention. Although the biological role of particular health behaviours in the prevention of breast cancer remains unclear, these behaviours may represent adaptive coping resources to be accessed in times of personal stress (Ingledew et al., 1996).

The long-term role of specific coping strategies, particularly cognitive avoidance, requires further investigation in terms of specific outcomes such as reduced psychological distress and cancer worry. Interventions can then be aimed at promoting the use of those strategies that are shown to be adaptive in the long-term.

3.9.5 Are there any needs for information or psychosocial support that are not being met by the existing service at the familial breast cancer clinic?

Every woman in this study indicated at least one support need that was not being met by the existing clinical service. Of top priority was the provision of information on a wide variety of scientific and psychosocial issues related to familial risk of breast cancer. There was a general preference for this information to be presented by an expert via a group meeting with supplementary written materials.

Currently the support provided to these women is limited to an annual clinic appointment focusing on breast cancer screening. This need for additional support services may be further strengthened by growing number of referrals to the familial breast cancer clinic. Without a corresponding increase in resources, this places increasing pressures on the clinic, whose focus is likely to be new referrals for genetic risk counselling. This results in less frequent and shorter follow-up appointments for women who have been attending the clinic for several years.

3.9.6 Methodological Issues

3.9.6a Participants

There were several methodological issues concerning the sample of women who participated in the study.

Responses to the feedback questionnaire identified two protocol violations (i.e. two women had undergone genetic testing for a breast cancer gene mutation that had been identified in their family). This suggests that the clinical records used to check participants' eligibility for the study were not up-to-date concerning genetic testing. However, the data collected from these two women both in terms of their contributions to the focus groups and responses to the feedback questionnaire were retained in the analysis. Although, the inclusion of these two women rendered the sample less homogenous with respect to the clinical services they had received, it was deemed important to include the data they had provided. When interpreting the data, it is important to consider the different experience of the two women and the effect it may have had on the data they provided (e.g. the type of information or psychosocial support they required).

The data collected both from the telephone focus groups and feedback questionnaire incidentally identified some variables that may have affected the participants' responses, particularly in terms of the levels of distress they reported experiencing: the time since the women's last appointment at the familial breast cancer clinic varied greatly (i.e. from a few days ago up to 18 months ago), many women described having family histories of other forms of cancer, six women were health professionals, two were currently suffering from ill health and one woman did not perceive herself to be at increased risk of breast cancer.

In addition the participants described different experiences of breast cancer in the family, which seemed to shape their view of breast cancer as a disease. Research in women at increased risk of breast cancer suggests that personal experience of breast cancer mediates the relationship between beliefs about the disease and certain psychological outcomes (Rees, 2002, personal communication). Other studies have also shown that these beliefs are associated with the use of specific coping strategies (Heijmans, 1998; Scharloo et al., 1998). Therefore, it may be important in future research in women who have been living with an increased risk of breast cancer for a number of years to assess the impact of different family histories of breast cancer and experiences of the disease in the family on various psychosocial factors such as psychological distress and coping strategies.

3.9.6b Moderator guide

The participants uncovered a number of difficulties during the telephone focus groups with questions contained in the moderator guide. Despite briefing participants on the topics for discussion beforehand, several women commented on

the difficulty in answering the questions without sufficient time for consideration. In addition, particular questions posed specific problems for participants. For example, one woman found it difficult to identify the everyday effects of living with an increased risk of breast cancer as she had lived all her life with the knowledge that breast cancer was in the family. Therefore, it may have been better to acknowledge these possible difficulties with particular questions before the questions were posed, in order to reassure participants and encourage them to consider the questions carefully. Several participants also expressed difficulties discussing the question: "Overall, would you say that knowing about an increased risk of breast cancer in the family has had a positive or negative effect on your life?". They found it difficult to regard any aspects of having a family history of breast cancer as positive. It may have been better to separate the positive and negative aspects of this question. The moderator could ask about the negative before the positive aspects so as not to assume that there were necessarily any positive effects of living with an increased risk of breast cancer.

3.9.6c Group dynamics

As the moderator holds a key role in eliciting the data from focus groups (Vaughn et al., 1996), their input could be an unavoidable confounding factor in participants' responses. The dynamics of each focus group varied slightly in that some required more moderator input than others. In the few groups where the participants took a while to "warm up", the moderator had to repeat and rephrase the initial questions in order to elicit any response. In other groups where all of the participants had a vast amount to contribute from the outset, the moderator channelled her efforts into directing the discussion and probing for deeper insights. Although the moderator attempted to monitor how often each participant in the group had contributed so the quieter participants could be directly encouraged to respond, a few groups had one participant that clearly contributed less than the other group members. It could be this minority that had reported finding it difficult to make their opinions known. Despite these differences in moderator input, all participants were pleased with the way in which the moderator handled their group's discussion.

3.9.6d Telephone conferencing

Although the telephone focus groups generally proceeded smoothly, several unanticipated technical difficulties with the telephone conferencing system were

experienced in a minority of groups. Firstly, some participants could not be heard clearly during the focus group, which rendered the sound quality of the audiotape to be relatively poor. Secondly, there was always a small amount of dialogue that was not recorded due to the telephone conferencing operator turning the audiotape to begin recording on the second side. Thirdly, one transcript was incomplete, as the operator had failed to turn the audiotape over. In addition, the telephone operator accidentally disconnected two participants during the groups. One woman was reconnected after only a few minutes and the other woman, who could not be reconnected, was telephoned individually by the moderator following the session. Feedback on these technical difficulties was given to Community Network, the organisation who operated the telephone conference calls.

3.9.6e Qualitative analysis

Analysing the focus group data was a very lengthy and rigorous process which posed unique difficulties. Despite the fact that the themes were only developed by one researcher, the inter-rater reliability of the independent quote to theme assignment between pairs of the three raters was shown to be good, according to published guidelines (i.e. Altman, 1991). The three researchers, however, did experience several difficulties during the qualitative analysis process. During the initial stage of identifying informative quotes, it was difficult to distinguish between quotes that were evidence of an everyday effect and quotes that referred to the coping strategy adopted (e.g. "I check myself every time I have a bath"). This type of difficulty was resolved either through discussion or by taking the view of the majority of raters. In addition, much discussion between the researchers during this stage was concerned with the inclusion of isolated quotes, which simply expressed agreement with a previous remark, but were meaningless on their own (e.g. "I agree as well"). All three raters agreed not to extract such quotes for use in the qualitative analysis. During the stage where the quotes were independently assigned to the themes, the two researchers often found it difficult to assign each quote to one theme only, when they deemed the quote to be relevant to more than one theme. In such cases, the quote was assigned to the one theme to which the rater judged it to be most important.

3.9.7 Further research

There are a number of potentially important issues for further investigation that have arisen from this exploratory research. These include the prevalence of and type of psychological distress and needs for information on issues related to familial risk of breast cancer and psychosocial support. Further research is needed to confirm and expand on the findings from this small selected sample in a larger sample of women living with an increased risk of breast cancer.

Chapter 4: Cross-sectional Study to Investigate the Impact of Appraisal, Coping Style, Social Support and Breast Cancer Cues on Psychological Distress in Women Living with an Increased Risk of Breast Cancer

4.1 Introduction

The telephone focus group study (Chapter 3) explored the psychosocial effects of living with an increased risk of breast cancer for a number of years. It provided qualitative evidence of between- and within-individual differences in terms of levels of distress and the coping strategies adopted and between-individual variation in the impact of breast cancer cues on levels of distress. It also highlighted a need for information about breast cancer-risk related issues and psychosocial support.

The results of the telephone focus group study together with a review of the psychological literature, particularly on women with a family history of breast cancer, identified areas that warranted further quantitative investigation in a larger sample of women living with an increased risk of breast cancer.

A number of key variables were identified that could impact on the relationship between psychological distress and living with an increased risk of breast cancer: appraisal, coping style, social support and breast cancer cues.

Appraisal is concerned with a person's judgements about the importance of a particular situation for them and about whether they have adequate resources to cope (Folkman & Greer, 2000). Research in women with a family history of breast cancer has assessed appraisal in terms of perceived risk of developing breast cancer (e.g. Evans et al., 1994; Lloyd et al., 1996; Cull et al., 1999; Watson et al., 1999; Meiser et al., 2001b; Bish et al., 2002) and perceived control over developing breast cancer (e.g. Audrain et al., 1997). It has provided evidence that appraisal is related to psychological distress, as women who perceive themselves to be at high risk of breast cancer (or who overestimate their risk) and those who perceive less control over their risk are likely to experience greater levels of psychological distress. These findings were supported by the results of the telephone focus group study (e.g. "I'm not entirely convinced that I am at increased risk...my mother was diagnosed as having breast cancer when she was in her mid-sixties and I am of the opinion that it could probably be anybody...it's not putting us at an increased risk...I don't think

about it all the time”; “...it’s important to me to feel that there are some things that I can take a bit of charge over”).

The results of the telephone focus group study suggested that these women adopted a variety of coping strategies at different times and in different situations associated with their increased risk of breast cancer. Coping is a complex variable to which there are two main approaches in the psychological literature: coping process and coping style. Coping process refers to coping as a state, which is influenced by context and time (Lazarus, 1993). In contrast, coping style refers to coping as a stable trait or disposition and emphasises the consistency of coping across different situations and over time (Lazarus, 1993). Although the coping process approach was favoured by the results of the telephone focus group study, it would not have been appropriate to assess coping process in a cross-sectional survey. Given the multiple influences on coping process and the lack of appropriate measures to assess coping processes specifically in women with a family history of breast cancer, research in this population has tended to investigate coping as a style. Monitoring and Blunting (Miller, 1987) are dimensions of coping style that have been assessed in several studies of women with a family history of breast cancer (e.g. Schwartz et al., 1995; Lerman et al., 1996; Audrain et al., 1997; Cull et al., 1999). Monitoring assesses a style of coping with threat-related cues by information-seeking, whereas Blunting describes the avoidance of such cues (Miller, 1987). These dimensions of coping style are particularly relevant to women living with an increased risk of breast cancer population and have already been linked to their levels of psychological distress (i.e. Schwartz et al., 1995; Lerman et al., 1996; Audrain et al., 1997). A new measure, The Uncertainty Response Scale (URS), has recently been developed to assess styles of coping with uncertainty (Greco & Roger, 2001). A wealth of research using experimental manipulations of uncertainty has provided evidence that uncertainty is a powerful stressor (Greco & Roger, 2001). The URS was developed in an attempt to investigate the role of personality factors (i.e. coping style) in influencing responses to uncertain situations. The measure assesses coping with uncertainty in terms of emotional and cognitive responses. It may be particularly pertinent to assess these dimensions of coping style in women who are living with the multiple uncertainties of having an increased risk of breast cancer.

Social support is a general term referring to the various forms of support given by a person’s social contacts including emotional and practical support (Weinman et al., 1995). It is typically considered to be “a resource or asset which may be mobilized in times of crisis to protect against threats to health” (Weinman et al., 1995). The findings of the telephone focus group study highlighted the role of

social support in coping with an increased risk of breast cancer: "...with having two sisters we discuss it an awful lot which I think helps enormously because we are all in the same position and I think we get a lot of strength from the fact that we all discuss it and we are all very close". The small number of studies to date that have assessed social support in women with a family history of breast cancer (i.e. Kash et al., 1992; Gagnon et al., 1996) have provided evidence that low levels of perceived social support both in terms of quantity and quality are associated with greater levels of psychological distress.

Breast cancer cues are internal (e.g. changes in the breast) or external (e.g. media reports about breast cancer) events which may prompt an individual to think about their increased risk of breast cancer (Appleton et al., 2000). The results of the telephone focus group study suggested that fluctuations in levels of distress over time were in response to breast cancer cues such as approaching the time of a breast cancer screening appointment. This supports the findings of research in women with a family history of breast cancer where the high levels of psychological distress that were experienced immediately prior to routine mammography, were reduced after receiving normal results (Valdimarsdottir et al., 1995).

In addition to the key variables, several exploratory variables were identified from the results of the telephone focus group study and the literature review which could affect levels of psychological distress in these women: sociodemographic variables, family history details, somatic symptoms and psychiatric history. Regarding somatic symptoms, there was a concern that an increase in vigilance to their health could result in these women experiencing a greater level of somatic symptoms. The analysis of these variables was subsidiary to the key variables which remained the main focus of the study.

4.2 Aims

The aims of the study were to:

1. Assess the prevalence of general psychological morbidity (in terms of GHQ-12 probable psychiatric "caseness") among women living with an increased risk of breast cancer.
2. Assess the psychological status of women living with an increased risk of breast cancer in terms of general psychological distress (somatic symptoms) and breast

cancer-specific distress (intrusive and avoidant thoughts about breast cancer risk and worry about breast cancer risk-related issues).

3. Assess the prevalence of information needs and preferences in women living with an increased risk of breast cancer.
4. Investigate the impact of appraisal, coping style, social support and breast cancer cues on general psychological distress (GHQ-12 “case-level” distress) and breast cancer-specific distress (intrusive and avoidant thoughts about breast cancer risk and worry about breast cancer risk-related issues) in women living with an increased risk of breast cancer.

4.3 Hypotheses

The hypotheses tested related to the 4th aim of the study.

1. Appraisal:

- a. Women who perceive themselves to be at a greater risk of developing breast cancer will show greater levels of psychological distress than women who perceive themselves to be at a lower risk.
- b. Women who perceive themselves to have less control over their risk of developing breast cancer will show greater levels of psychological distress than women who perceive themselves to have greater control over their risk.

2. Coping Style:

- a. Women with a high Monitoring coping style will show greater psychological distress than women with a low Monitoring coping style.
- b. Women with a high Monitoring coping style will show greater intrusive thoughts about breast cancer than women with a low Monitoring coping style.

- c. Women with a high score on Emotional Uncertainty will show greater psychological distress than women with a low score on Emotional Uncertainty.

3. Social Support:

Women who are less satisfied with their social supports will show greater psychological distress than women with greater satisfaction with their social supports.

4. Breast Cancer Cues:

Women who are approaching the age when their mother was diagnosed with breast cancer will show greater psychological distress than women who are much younger or older than their mother was at her diagnosis.

4.4 Design

This was a cross-sectional study in which participants were assessed by postal questionnaire. It was not practical to ask participants to complete the questionnaire when they attended the familial breast cancer clinic as their appointments were at least at yearly intervals. Therefore, a postal methodology was deemed to be the most appropriate way of collecting data from a large number of participants living within a wide radius and in a relatively short space of time. Postal questionnaires have been used successfully by a number of studies in women with a family history of breast cancer (e.g. Cull et al., 1998; Hopwood et al., 2001; Watson et al., 1999).

4.5 Participant selection

The Department of Clinical Genetics (Western General Hospital, Edinburgh) maintains a database of women with a family history of breast cancer in South East Scotland who have received genetic risk counselling. All women who met the study criteria in Table 4.1 were invited to participate.

Table 4.1: Eligibility criteria for the cross-sectional study

Inclusion criteria:

- Current attendance at the Ardmillan Familial Breast Cancer Clinic.
- Has attended the Ardmillan Familial Breast Cancer Clinic for at least two years.

Exclusion criteria:

- A previous diagnosis of cancer.
- Has had prophylactic surgery.
- Has undergone genetic testing.
- Participation in any psychosocial research in relation to their family history of breast cancer in the last six months.
- Current participation in the International Breast Cancer Intervention Study (IBIS); Magnetic Resonance Imaging (MRI) Trial or the Cancer Genetics in the Community Trial.

Additional exclusion criteria as assessed by their General Practitioner (GP):

- Currently suffering from serious physical illness.
- Currently suffering from alcoholism, schizophrenia or organic brain damage.

4.6 Measures

A copy of the cross-sectional study questionnaire is in Appendix II, page 15.

4.6.1 Sociodemographic variables

The following sociodemographic variables were recorded: age, number of years of attendance at the familial breast cancer clinic, marital status, number/age/gender of children, education, ethnicity, occupation and current medical conditions.

4.6.2 Family history of breast cancer

Family history of breast cancer was assessed in terms of: the number of relatives diagnosed with breast cancer, which relatives had been diagnosed with breast cancer, the age at which they had been diagnosed, their current health status and the number of these relatives personally known to the respondent.

4.6.3 Psychiatric history

Two items were used to assess psychiatric history: “Have you ever been treated for nervous or emotional problems such as anxiety or depression in the past at any time?”, “Have you ever had an admission to hospital for nervous problems?”. Responses were on a simple yes/no format, where participants were asked to provide further details if they answered yes. These items have previously been used in cancer outpatients (Cull et al., 2001b).

4.6.4 General psychological distress

4.6.4a 12-item General Health Questionnaire (GHQ-12)

The 12-item version of the GHQ is a first-stage screening test to detect current psychiatric disorders in individuals from community and non-psychiatric clinical populations (Goldberg & Williams, 1991). Respondents are asked about recent and current disruptions in their normal functioning and not enduring traits (Goldberg & Williams, 1991). As a screening test, the GHQ-12 was not designed to produce clinical diagnoses, but to estimate the probability of psychiatric illness (Goldberg & Williams, 1991). A clinical interview would be needed to confirm a psychiatric diagnosis for those who screen positive (Goldberg & Williams, 1991). The GHQ-12 is a standardised measure which has been subjected to thorough psychometric testing (Goldberg & Williams, 1991). It has been shown to be as effective a screening measure as the longer 28-item version of the GHQ (Goldberg et al., 1997). Responses were scored using the GHQ method of scoring (0,0,1,1) and were summed to produce a total score of 0-12. A threshold score of ≥ 3 was used to indicate probable psychiatric “caseness”. This threshold has previously been applied to general population (i.e. Weich et al., 2001) and general practice samples (i.e. May, 1992; Plummer et al., 2000), families undergoing genetic testing for BRCA1 (Watson et al., 1996) and first-time attendees of breast cancer genetic risk counselling (Watson et al., 1998,1999).

4.6.4b Somatic symptoms

The somatic symptoms subscale is one of four subscales that form the 28-item version of the General Health Questionnaire (GHQ-28) (Goldberg & Hillier, 1979). The ethics committee refused permission for the use of the GHQ-28 in this study on the grounds that the depression subscale items might cause distress in a postal survey. They did give permission for the somatic symptoms subscale to be

retained for exploratory purposes. The somatic symptoms subscale does not generate a psychiatric diagnosis, but rather denotes “dimensions of symptomatology” (Goldberg & Williams, 1991). It contains seven items (that do not repeat any of the items in the GHQ-12) which focus on recent and current somatic symptoms such as “a feeling of tightness or pressure in your head”. A number of studies have examined the psychometric properties of the GHQ-28 (Goldberg & Williams, 1991). Responses were scored using the GHQ method of scoring (0,0,1,1) and were summed to produce a total score of 0-7. Data on the somatic symptoms subscale is available for women in the general population attending a breast screening program (Ellman et al., 1989) and first-time attendees of breast cancer genetic risk counselling (Hopwood et al., 1998). Results on the subscale have been recorded in different ways: as a score of at least one point (i.e. Ellman et al., 1989) and using the GHQ-28 threshold of ≥ 5 (i.e. Hopwood et al., 1998).

4.6.5 Breast cancer-specific distress

4.6.5a Impact of Event Scale (IES)

This 15-item scale was originally developed “to assess current subjective distress for any life event” (Horowitz et al., 1979). It consists of two subscales: Intrusion (7 items) which focuses on invasive images/thoughts and Avoidance (8 items) which focuses on evasion of certain thoughts, feelings and reminders (Horowitz et al., 1979). The scale has been modified for use in women at increased risk of breast cancer to determine levels of breast cancer-specific distress in terms of intrusive and avoidant thoughts about breast cancer risk in the past week (Kash et al., 1992). Responses are on a 4-point Likert scale which were assigned weighted scores of 0 (not at all), 1 (rarely), 3 (sometimes) and 5 (often). Scores were summed to produce two subscale scores: Intrusion (0-35) and Avoidance (0-40). These subscale scores were also summed to produce a total Impact of Event Scale score of 0-75 where higher scores represent greater breast-cancer specific distress. Following the work of others using this instrument in women at increased risk of breast cancer (i.e. Lloyd et al., 1996; Thewes et al., 2001), an opt-out box was included for women who had not thought about their risk of breast cancer in the past week. Systematic psychometric testing of the scale has confirmed that it is reliable, valid and acceptable in women at increased risk of breast cancer (Thewes et al., 2001). The scale has been extensively used in women with a family history of breast cancer (e.g. Audrain et al., 1997, 1999; Baider et al., 1999; Gagnon et al., 1996; Lerman et al., 1993, 1994, 1995, 1996; Lloyd et al., 1996; McCaul et al., 1998; Meiser et al., 2000,

2001a & b; Schwartz et al., 1998, 1999b; Smith et al., 1999; Valdimarsdottir et al., 1995; Watson et al., 1996, 1999; Zakowski et al., 1997, 2001).

4.6.5b *Worry about breast cancer risk-related issues*

Using the qualitative results of our previous telephone focus group study, seven individual items were developed to reflect a range of probable concerns of this population regarding their increased risk of breast cancer. Participants were asked to indicate on a 4-point Likert scale (not at all/ a little/moderately/very worried) how worried they had been about each of the following issues in the past week: developing breast cancer anytime now/in the future, the possibility of having to make future decisions about their increased risk such as genetic testing or prophylactic surgery, the frequency of clinic appointments, dying from breast cancer and leaving their children, their children's risk of developing breast cancer, other concern).

4.6.6 Information needs and preferences

A 21-item checklist was designed using issues raised by the telephone focus group study to assess the participants' needs and preferences for information related to familial risk of breast cancer. Participants were asked if they would be interested in 11 different topics of information related to familial risk of breast cancer (scientific research concerning breast cancer genetics/screening/treatment, research conducted at the Ardmillan familial breast cancer clinic, genetic testing, prophylactic surgery, hormone replacement therapy, the oral contraceptive pill, maintaining a healthy lifestyle, ways to help you deal with any stress you may be experiencing, another topic) and four different formats for receiving information (written, group meeting for women attending the familial breast cancer clinic/for women and their families, telephone discussion group). They were asked to indicate their interest by endorsing the appropriate item. An option was also provided for participants to endorse if they were not interested in any of the formats listed. The number of topics of information and intervention formats endorsed were summed separately to produce two totals.

4.6.7 Appraisal

4.6.7a *Perceived risk*

A single item assessed perceived risk of developing breast cancer in comparison with the general population: "Do you think that your risk of ever

developing breast cancer is...?”. Responses were on a 4-point Likert scale (lower/the same as/ slightly higher/much higher than the general population). Similar items have previously been used to assess perceptions of risk in women with a family history of breast and/or ovarian cancer (e.g. Audrain et al., 1997; Lerman et al., 1993, 1994; Lloyd et al., 1996; Watson et al., 1999).

4.6.7b *Perceived likelihood*

A single item was used to measure perceived likelihood of developing breast cancer: “How likely do you feel it is that you will ever develop breast cancer?”. Responses were on a 5-point Likert scale (very unlikely/unlikely/likely/very likely/inevitable). A number of studies have used similar items to assess perceived likelihood in women with a family history of breast cancer (e.g. Gagnon et al., 1996; Kent et al., 2000; Lerman et al., 1993, 1994) and ovarian cancer (e.g. Cull et al., 2001a).

4.6.7c *Perceived change in risk*

In order to determine any perceived change in breast cancer risk since first attending the familial breast cancer clinic, a single item was devised specifically for this study: “Since you first started attending the Ardmillan Familial Breast Cancer Clinic do you think that your risk of ever developing breast cancer has...?”. Response-options were: increased/decreased/stayed the same/not sure.

4.6.7d *Perceived control*

A single item was used which has been developed to assess perceived control over developing breast/ovarian cancer in women at increased risk (“How much control do you feel you have over whether you develop breast cancer?”) (Audrain et al., 1997). Responses were on a 4-point Likert scale (none at all/a bit/moderate/a lot).

4.6.8 Psychological traits: coping style

4.6.8a *Miller Behavioural Style Scale (abbreviated version) (MBSS)*

The MBSS was designed to assess styles of coping with threat-related cues (Miller, 1987). The scale assesses two dimensions: Monitoring (information seeking) and Blunting (distraction). Respondents are asked how they would react to several different stressful scenarios, with a choice of four Monitoring options and four Blunting options. They can endorse as many responses as are applicable. Internal consistency of the Monitoring and Blunting subscales in terms of alpha coefficients have been reported as .75 to .79 and .67 to .69 respectively (Miller, 1987). Test-retest

reliability has been shown to be satisfactory at .72 (Monitoring) and .75 (Blunting) (Miller, 1987). An abbreviated version of the scale has been developed to have greater face validity, particularly for British medical patients (Steptoe, 1989). This version of the scale consists of two of the four original scenarios (i.e. visit to the dentist, threat of job loss) both followed by four Monitoring options (e.g. "I would ask the dentist exactly what he or she was going to do") and four Blunting options (e.g. "I would try to think about pleasant memories"). Total scores for each of the two dimensions are produced by summing the number of Monitoring or Blunting options endorsed: Monitoring (range 0-8), Blunting (range 0-8). Greater scores on each of these dimensions represent more Monitoring or Blunting (Miller, 1987). The abbreviated MBSS has been shown to adequately reflect responses to the full version of the scale and to be acceptable in samples of British students and cancer patients (Steptoe, 1989). It has also been used in women who have recently undergone a breast biopsy (Andrykowski et al., 2001), women at increased risk of breast cancer (Cull et al., 1999) and ovarian cancer (Cull et al., 2001a; Wardle, 1995).

4.6.8b *Uncertainty Response Scale (URS)*

The URS is a recently developed 48-item scale designed to measure "styles of coping with uncertainty" (Greco & Roger, 2001). It attempts to predict individual or personality differences in responses to uncertain situations (Greco & Roger, 2001). The scale consists of three factors of which two were used in this study: Emotional Uncertainty (EU) (15 items regarding emotional responses to uncertainty e.g. "I get worried when a situation is uncertain") and Cognitive Uncertainty (CU) (17 items regarding cognitive responses to uncertainty e.g. "When I feel uncertain, I try to take decisive steps to clarify the situation"). Responses to the 32 items used in this study were on a 4-point Likert scale: never/sometimes/ often/always. Scores were summed on EU and CU to produce totals ranging from 15-60 and 17-68 respectively. This scale has undergone thorough psychometric analysis including internal consistency (alpha coefficient) of .89 (EU), .85 (CU) and test-retest reliability of .79 (EU) and .80 (CU) (Greco & Roger, 2001). In the present study, the high internal consistency of the two factors was confirmed: alpha coefficients of .92 (EU) and .86 (CU). The Emotional Uncertainty factor has been found to be predictive of both psychological and physiological reactions to the expectation of an experimental threat (Greco & Roger, 2001) and has also been shown to predict deteriorating health status in undergraduate students (Greco & Roger, 1999).

4.6.9 Social support

The 6-item version of the Social Support Questionnaire (SSQ6) was designed to assess two dimensions of perceived social support: number (perceived availability) of supports and satisfaction with supports (Sarason et al., 1987). For each item, respondents are asked to list all the people (by giving the person's initials and their relationship to the respondent), up to a maximum of nine, they can rely on for a particular type of support (e.g. "Whom can you really count on to distract you from your worries when you feel under stress?"). They are then required to rate on a 6-point scale (from 6 = very satisfied to 1 = very dissatisfied) their level of satisfaction with the type of support indicated in the question. The scale produces two total scores by summing the number of supports listed (0-54) and the ratings of satisfaction with supports (6-36). This version of the scale has been subjected to thorough psychometric testing and has shown high internal consistency of both subscales (alpha coefficient = .90 to .93) (Sarason et al., 1987). As no norms or thresholds have been derived for the SSQ6, individual scores represent relative measures of support, rather than indicators of low or high levels of perceived social support (Weinman et al., 1995). This version of the scale has been used in a number of populations including university students (Steptoe & Wardle, 2001) and the male partners of HIV-positive men (Gray & Hedge, 1999).

4.6.10 Breast cancer cues

Directed by the results of the previous telephone focus group study, a checklist of 10 items was developed to assess whether participants had experienced any breast cancer cues in the past week. The items included: "Have you read, watched or listened to anything about breast cancer?"; "Have you examined your breasts?"; "Have you been waiting for the results of mammogram or breast biopsy?". The number of items endorsed was summed to produce a total from 0-10.

4.7 Procedure

Ethical approval for the study was obtained from the regional ethics committee. The GPs of all women meeting the study criteria were contacted by letter. They were asked to confirm whether their patients could be invited to participate on the basis of the additional exclusion criteria (Table 4.1). They were sent a copy of the

letter of invitation and information sheet designed for participants. A response was requested by Freepost envelope or fax. GPs who had not responded within two weeks were sent a reminder letter and were telephoned weekly for up to two further weeks if they still had not replied.

All women opted in to the study by their GP were then sent a letter inviting them to take part in the study together with an information sheet and consent form. They were asked to reply using the Freepost envelope provided. Reminder letters were sent to all non-respondents after three weeks. Those who consented were sent a questionnaire, which they were asked to return within two weeks in the Freepost envelope provided. If a completed questionnaire was not received from them within three weeks, the participant was sent a reminder letter.

The GP of any participant who scored above the threshold (i.e. ≥ 3) on the GHQ-12 was promptly notified by letter of their patient's score.

4.8 Statistical analysis

The distribution of all continuous variables was assessed to determine their parametric or non-parametric nature. The appropriate descriptive statistics were generated to describe the study participants. Differences between two independent groups were analysed with independent samples t-tests (2-tailed), Mann-Whitney, chi-square or Fisher's exact tests.

Univariate analyses in terms of simple linear or logistic regression were initially conducted to test the extent to which the hypothesised or exploratory variables predicted the psychological distress variables.

The results of the univariate analyses informed the selection of variables for multivariate analysis. Multiple linear regression (stepwise selection) or multiple logistic regression (forward stepwise selection using the likelihood ratio test) were used to determine the combination of hypothesised/exploratory variables that best predicted the eight psychological distress variables. The criterion for entering variables into a model was $p < 0.05$ and for removing variables was $p > 0.10$.

The absence of one or more scores on a scale resulted in that total score being classified as missing. A significance level of 0.05 was used throughout.

When conducting multiple statistical tests on a set of data, it is likely that some results will be significant by chance (Campbell & Machin, 1999). The analysis was directed by the study hypotheses, thus limiting the number of statistical tests. The results of secondary or exploratory analyses should be interpreted with caution

(Altman, 1991) as the results require confirmation in further studies (Campbell & Machin, 1999).

The data were analysed using SPSS for Windows version 10.00 (1999).

4.9 Results

4.9.1 Participants

Figure 4 shows the participant recruitment to the study.

Of the 2455 women identified from the database of women with a family history of breast cancer in South East Scotland, there was insufficient data available for 414 women to confirm their eligibility. Of the remaining women, 1631 did not meet the eligibility criteria (Table 4.1): 509 had been discharged from the Ardmillan Familial Breast Cancer Clinic; 525 had attended the clinic for less than two years; 41 had a previous diagnosis of cancer; 15 had prophylactic surgery; 8 had genetic testing; 348 had participated in psychosocial research in relation to their family history of breast cancer in the last six months; 176 were participating in the IBIS, MRI trial or Cancer Genetics in the Community Trial; 9 for other reasons.

Of the 410 women who met the initial eligibility criteria, seven women were not registered with their listed GP and details of their new GP were not recorded at Lothian Health Board. Therefore, these women were excluded as their GPs could not be contacted to confirm their eligibility. Twenty-eight of the remaining women were excluded on the basis of information from their GP (GPs could list more than one reason): 4 had a previous diagnosis of cancer; 8 had a serious physical illness; 3 had alcoholism, schizophrenia or organic brain damage; 17 for other reasons. In addition, one GP refused to disclose their patient's eligibility for entering the study. Two GPs did not respond about their patients despite two letters and two telephone messages.

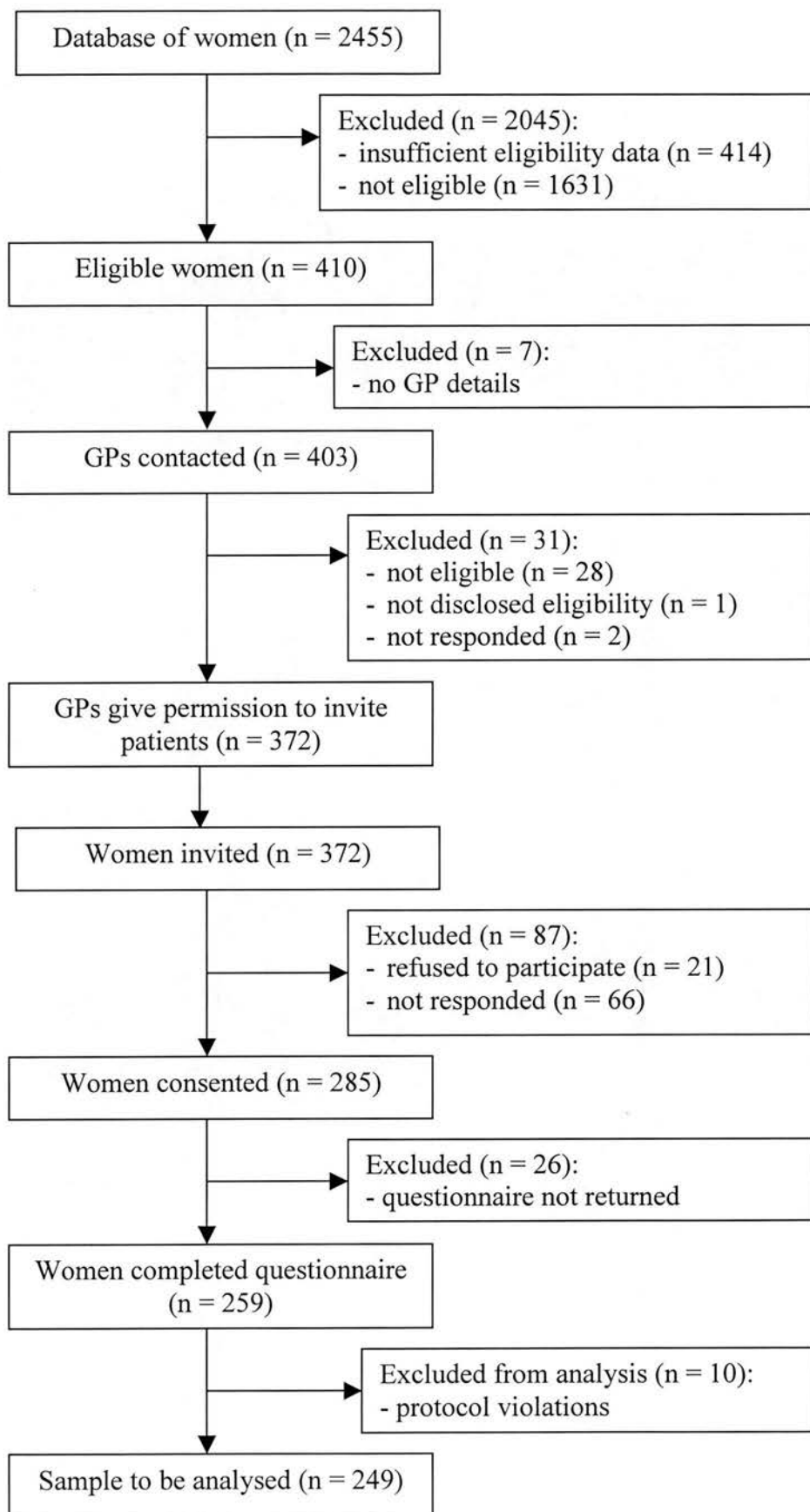


Figure 4: Participant recruitment to the cross-sectional study

There were 372 women who met the initial eligibility criteria and whose GPs gave permission for them to be invited. Of the women who were invited to participate, 21 refused and 66 did not respond to the initial invitation or reminder letter. Of the 285 who consented, 259 returned a completed questionnaire. In 10 women, protocol violations were identified and their data were removed from the analysis (four were recent recruits to IBIS, two were recent recruits to the MRI trial, two had been discharged from the clinic, one had not yet attended for her first screening appointment, one was participating in the Cancer Genetics in the Community Trial). The sample to be analysed was 249. The participation rate for the study was 69% (249/362). There were no significant differences between participants ($n = 249$) and non-participants ($n = 161$) on age and number of years attendance at the familial breast cancer clinic.

4.9.2 Sociodemographic variables

Participants ranged in age from 28-62 years (mean = 43.4, SD = 6.5). The mean number of years they had been attending the familial breast cancer clinic was 4.5 (SD = 1.7, range = 2.1-7.9). Eighty percent of participants had at least one child (range = 0-4) and of those women, 71% had at least one daughter (range 0-3). The children ranged in age from two months to 36 years. Eighty-two percent of participants ($n = 200$) were married or living with a partner, 9% ($n = 23$) were divorced or separated, 8% ($n = 20$) were single and two women (1%) were widowed. Thirty-three percent of participants ($n = 82$) had only received schooling until age 16, 15% ($n = 37$) had attended school/further education/training until age 18, 25% ($n = 61$) had received further education or training after age 18 and 27% ($n = 68$) were university graduates. All but one participant were of white ethnicity. Most participants were employed either full-time ($n = 114$, 46%), part-time ($n = 95$, 38%) or self-employed ($n = 1$) with 27 (11%) having home duties, seven were unemployed (3%) and five were retired (2%). Thirty percent of participants ($n = 73$) reported currently suffering from a medical condition. These conditions were diverse (e.g. multiple sclerosis, asthma, recent injury). A quarter of these women gave details of more than one condition.

4.9.3 Family history of breast cancer

The number of relatives of each participant who had been diagnosed with breast cancer ranged from 0-11 (mean = 2.3, SD = 1.3). For the woman with no

relatives with breast cancer, her increased risk of breast cancer arose from her family history of ovarian cancer. Of the 552 relatives listed as having breast cancer, 264 (48%) were first-degree relatives (e.g. sister: $n = 72$, 13%), 202 (37%) were second-degree relatives (e.g. aunt: $n = 136$, 25%) and 86 (16%) were more distant relatives (e.g. great aunt: $n = 35$, 6%). The age at which these relatives were diagnosed with breast cancer ranged from 24-95 years. The majority of these relatives had died from breast cancer ($n = 290$, 53%) whereas 16% ($n = 88$) had died from other causes, 4% ($n = 22$) were alive but unwell and 27% remained alive and well ($n = 148$). The mean number of these relatives personally known by participants was 2.1 (SD = 1.1, range = 0-6).

The mothers of 189 participants (76%) had been diagnosed with breast cancer. The mean age at which the mothers were diagnosed was 48.4 years (SD = 11.8, range = 26-82). At the time of this assessment, participants were in an age range from 34 years younger to 15 years older than the age at which their mother was diagnosed with breast cancer (mean = 5.64 years younger, SD = 10.85). A large proportion of the mothers had died from breast cancer ($n = 97$, 53%) or other causes ($n = 28$, 15%) whereas 28% ($n = 51$) were alive and well and 4% ($n = 7$) were alive but unwell.

4.9.4 Psychiatric history

Thirty-four percent of participants ($n = 82$) indicated that they had been treated for nervous or emotional problems in the past. These problems included anxiety (e.g. panic attacks), depression (e.g. post-natal), bereavement, agoraphobia, post-traumatic stress disorder, work-related stress, PMT and anorexia. The treatments described included medication, counselling and Cognitive Behavioural Therapy. Only eight women (3%) stated they had ever been admitted to hospital for nervous problems.

4.9.5 General psychological distress

The median GHQ-12 total score was 0 (range 0-12). Sixty-five women scored at least three on the GHQ-12 which meant that the prevalence of general psychological morbidity (in terms of GHQ-12 probable psychiatric "caseness") was 26%.

The mean score on the somatic symptoms subscale of the GHQ-28 was 1.38 (SD = 1.90, range 0-7). Forty-six percent (n = 113) of participants scored at least one on this subscale and 10% (n = 24) scored at least five.

As an aid to the interpretation of GHQ data from this uncontrolled study, comparative data derived from the literature are presented in Table 4.2.

4.9.6 Breast cancer-specific distress

Forty-four percent of the women (n = 109) indicated that they had thought about the risk of breast cancer in the past week and therefore completed the Impact of Event Scale.

There were no significant differences between those who completed the IES (IES group) and those who did not (no IES group) on GHQ-12 “case-level” distress, perceived control over developing breast cancer, total satisfaction with social supports and the difference between the age of mother at diagnosis of breast cancer and the current age of the woman.

However, there were significant differences between the IES and no IES groups on Monitoring ($t = -3.37$, $df = 241$, $p = .00$), Emotional Uncertainty ($z = -4.30$, $p < .00$) and somatic symptoms ($z = -2.57$, $p = .01$). The IES group had significantly higher mean scores on Monitoring (4.25 compared to 3.54) and higher median scores on Emotional Uncertainty (32 compared to 29) and somatic symptoms (1 compared to 0). There were significant differences between the IES and no IES groups on perceived likelihood of developing breast cancer (likely/unlikely) ($\chi^2 = 16.38$, $df = 1$, $p < .00$) where only 24% of those women who perceived their risk as unlikely, had completed the IES. Significantly more women in the IES group than no IES group were worried about a variety of breast cancer risk-related issues: developing breast cancer now (worried/not worried) ($\chi^2 = 68.12$, $df = 1$, $p < .00$); developing breast cancer in the future ($\chi^2 = 87.43$, $df = 1$, $p < .00$); dying from breast cancer and leaving their children ($\chi^2 = 70.47$, $df = 1$, $p < .00$); their children’s risk of developing breast cancer ($\chi^2 = 31.50$, $df = 1$, $p < .00$).

The mean scores were 7.39 for Intrusion (SD = 6.07, range = 0-27), 11.12 for Avoidance (SD = 7.82, range = 0-30) and 18.48 for the total IES score (SD = 12.35, range = 0-57). As an aid to the interpretation of IES data from this uncontrolled study, comparative data derived from the literature are presented in Table 4.2.

Table 4.2: Comparative data for general psychological distress, somatic symptoms and breast cancer-specific distress

Variable	Measure	Author	Sample*	Summary of Results
General psychological distress	GHQ-12 (Threshold ≥ 3)	May (1992)	222 patients attending their GP surgery	50% were experiencing "case-level" distress
		Watson et al. (1998)	91 women six months after breast cancer genetic risk counselling	34% were experiencing "case-level" distress
		Watson et al. (1999)	249 women 12 months after breast cancer genetic risk counselling	27% were experiencing "case-level" distress
		Plummer et al. (2000)	1710 patients attending their GP surgery	36% were experiencing "case-level" distress
		Weich et al. (2001)	Women participating in the British Panel Household Survey	30% were experiencing "case-level" distress
Somatic symptoms	GHQ-28 subscale	Ellman et al. (1989)	287 women three months after attending routine breast cancer screening (no abnormalities were found)	34% scored at least one point
		Hopwood et al. (1998)	148 women 3 months after breast cancer genetic risk counselling	12% scored at least five points
Breast cancer-specific distress	IES	Lloyd et al. (1996)	88 women 2-25 months after breast cancer genetic risk counselling	Intrusion: mean = 6.9 (SD 7.4) Avoidance: mean = 7.2 (SD 8.5) Total IES: mean = 14.1 (SD 14.3)
			62 women in the general population (age-matched controls)	Intrusion: mean = 1.1 (SD 3.5) Avoidance: mean = 1.3 (SD 3.8) Total IES: mean = 2.4 (SD 6.7)
		Watson et al. (1999)	249 women 12 months after breast cancer genetic risk counselling	Intrusion: mean = 7.77 (SD 6.09) Avoidance: mean = 9.48 (SD 7.95) Total IES: mean = 17.23 (SD 12.45)

* All samples were British

The most common worry regarding breast cancer was about developing breast cancer in the future: 61% of participants had been worried about this in the past week (Table 4.3). Thirty-eight percent had been worried about the possibility of having to make future decisions about their increased risk such as genetic testing or prophylactic surgery, 35% had been worried about developing breast cancer anytime now and 17% had been worried about the frequency of their appointments at the familial breast cancer clinic. Of the women that had children, 47% had been worried about their children's risk of developing breast cancer and 42% about dying from breast cancer and leaving their children. Other worries about breast cancer risk-related issues included HRT, breast symptoms and lifestyle issues. 181 women (73%) indicated that they had been worried in the past week about at least one of the seven issues related to breast cancer risk that were listed.

Table 4.3: Frequency of worries about breast cancer risk-related issues

Worry about:	Not at all worried	A little worried	Moderately worried	Very worried
Developing breast cancer in the future	97 (39%)	107 (43%)	39 (16%)	5 (2%)
The possibility of having to make future decisions about your increased risk such as genetic testing or prophylactic surgery	153 (62%)	68 (28%)	20 (8%)	6 (2%)
Developing breast cancer anytime now	161 (65%)	68 (28%)	14 (6%)	4 (2%)
The frequency of your appointments at the familial breast cancer clinic	205 (83%)	31 (13%)	8 (3%)	4 (2%)
Your children's own risk of developing breast cancer	104 (53%)	59 (30%)	22 (11%)	12 (6%)
Dying from breast cancer and leaving your children	116 (58%)	62 (31%)	14 (7%)	7 (4%)
Other	Not applicable	25 (66%)	7 (18%)	6 (16%)

4.9.7 Information needs and preferences

Participants expressed a widespread interest in receiving information on various topics related to familial risk of breast cancer (Table 4.4). The mean number of topics endorsed was 4.93 (SD = 2.49, range = 0-11). Ninety-five percent of participants (n = 236) indicated that they would be interested in receiving at least one of the 11 topics of information listed on the questionnaire. Some women also requested other topics of information which were not already listed. These included natural alternatives to HRT, other forms of cancer such as ovarian cancer and dietary advice.

The most popular format for receiving such information was as written information (n = 209, 85%). In contrast, less than half of participants (n = 98, 40%) expressed an interest in attending a group meeting in Edinburgh only for women attending the familial breast cancer clinic (where experts would present the information and be available to answer any questions), 21% (n = 52) were interested in attending such a group meeting where their families would also be able to attend and 11% (n = 26) were interested in telephone discussion groups with other women in the same situation (where expert information would be presented and they would have the opportunity to discuss the information as a group and ask any questions). The mean number of information formats endorsed was 1.56 (SD = 0.92, range = 0-4). Ninety-one percent of participants (n = 226) indicated that they would be interested in at least one of the four information formats listed. 20 women (8%) indicated that they were not interested in any of the information formats listed.

Table 4.4: Topics of information related to familial risk of breast cancer

Topic of Information	Frequency
Breast cancer genetics	179 (72%)
Research conducted at the Ardmillan Familial Breast Cancer Clinic	168 (68%)
Genetic testing	166 (67%)
Breast cancer treatment	157 (63%)
Breast cancer screening	148 (59%)
Maintaining a healthy lifestyle	123 (49%)
Hormone Replacement Therapy (HRT)	103 (41%)
Ways to help you deal with any stress you may be experiencing	101 (41%)
Prophylactic surgery	40 (16%)
The oral contraceptive pill	33 (13%)
Another topic	11 (4%)

4.9.8 Appraisal

Most participants thought that their risk of ever developing breast cancer was slightly higher ($n = 156$, 63%) or much higher ($n = 75$, 31%) than the general population whilst just 14 women (6%) thought their risk was the same as the general population and one woman thought her risk was lower than the general population.

Only a minority of participants felt that it was very unlikely ($n = 1$) or unlikely ($n = 75$, 31%) that they would ever develop breast cancer. In contrast, 55% ($n = 131$) thought that it was likely, 13% ($n = 32$) very likely and one woman thought that it was inevitable that she would ever develop breast cancer.

The vast majority of participants ($n = 186$, 76%) thought that their risk of ever developing breast cancer had stayed the same since they first started attending the familial breast cancer clinic. Forty women (16%) thought their risk had decreased, nine ($n = 4$ %) increased and 11 (5%) were not sure.

Although 37% ($n = 92$) of participants felt that they had no control over whether they ever developed breast cancer, 40% ($n = 98$) felt they had a bit, 21% ($n = 51$) a moderate amount and 2% ($n = 6$) felt they had a lot of control over ever developing breast cancer.

4.9.9 Psychological traits: coping style

The mean score for the Monitoring subscale was 3.84 ($SD = 1.65$, range = 0-8) and for the Blunting subscale was 1.97 ($SD = 1.35$, range = 0-6).

The mean Emotional Uncertainty score was 31.23 ($SD = 7.62$, range = 18-56) and the mean score for Cognitive Uncertainty was 46.03 ($SD = 7.44$, range = 29-67).

Data derived from these two coping style scales in published studies are presented for comparative purposes in Table 4.5.

4.9.10 Social support

The total number of social supports listed by participants ranged from 0-54 (mean = 22.19, $SD = 11.15$). Total satisfaction with supports ranged from 6-36 (mean = 30.84, $SD = 5.42$). A wide variety of social supports were listed including family members, friends, religious figures, work colleagues and pets. The three most frequently listed supports were: friend ($n = 1831$, 34.2%), husband/partner ($n = 975$, 18.2%) and sister ($n = 600$, 11.2%). Comparative data from the literature using the SSQ-6 are presented in Table 4.5.

Table 4.5: Comparative data for coping style and social support

Variable	Measure	Author	Sample*	Summary of Results
Style of coping with threat-related cues	MBSS (abbreviated version)	Steptoe (1989)	40 cancer patients	Monitoring: mean = 4.45 (SD 2.0) Blunting: mean = 2.98 (SD 1.6)
			80 undergraduate students	Monitoring: mean = 4.66 (SD 1.8) Blunting: mean = 1.43 (SD 1.3)
		Wardle et al. (1995)	358 women with a first-degree relative with ovarian cancer	Monitoring: mean = 4.05 (SD 1.69)
			378 women in the general population one year after routine ovarian cancer screening	Monitoring: mean = 4.07 (SD 1.69)
			186 women in the general population (controls)	Monitoring: mean = 4.17 (SD 1.77)
Style of coping with uncertainty	URS	Cull et al. (1999)	479 women prior to breast cancer genetic risk counselling	Monitoring: mean = 3.8 (SD 1.7) Blunting: mean = 1.9 (SD 1.2)
		Cull et al. (2001)	192 women prior to ovarian cancer genetic risk counselling	Monitoring: mean = 3.7 (SD 1.7) Blunting: mean = 1.9 (SD 1.2)
		Greco & Roger (2001)	162 female university students	Emotional uncertainty: mean = 17.23 (SD 6.85) Cognitive uncertainty: mean = 27.34 (SD 7.04)
Social support	SSQ-6	Gray & Hedge (1999)	35 partners of gay men with HIV-related disease	Total number of supports: mean = 17.85 (SD 13.29) Total satisfaction with supports: mean = 29 (SD 6.54)

* All samples were British

4.9.11 Breast cancer cues

One hundred and ninety-two women (77%) indicated that in the past week they had experienced at least one of the nine breast cancer cues listed. One hundred and eighteen women (61%) had examined their breasts, 116 (60%) had read, watched or listened to something about breast cancer, 32 (17%) had experienced a significant family event concerning breast cancer such the birthday of a deceased relative, 28 (14%) had spoken to a close relative or friend about their risk of breast cancer, 27 (14%) had relatives or friends who had been diagnosed or treated for breast cancer, eight (4%) had been waiting for the results of a mammogram or breast biopsy, six (3%) had received the results of a mammogram or breast biopsy and three (2%) had undergone a breast biopsy or related medical investigation. Thirty-eight women (20%) listed another breast cancer cue that they had experienced in the past week. These included participating in this study, the death of a relative or friend from cancer and experiencing breast symptoms.

4.9.12 Investigating psychological distress

The following sections of results relate to the fourth aim of the study and therefore tested the study hypotheses.

The hypothesised variables were: perceived risk; perceived likelihood; perceived control; Monitoring; Emotional Uncertainty; total satisfaction with social supports; difference between the age of mother at diagnosis of breast cancer and current age of woman.

The exploratory variables were: sociodemographic variables; psychiatric history; family history of breast cancer; GHQ-12 “case-level” distress; somatic symptoms; Blunting; Cognitive Uncertainty.

The psychological distress variables were: GHQ-12 “case-level” distress; Intrusion; Avoidance; total IES score; worry about developing breast cancer anytime now/developing breast cancer in the future/dying from breast cancer and leaving their children/their children’s own risk of developing breast cancer.

4.9.12a Predicting GHQ-12 “case-level” distress

Univariate analyses showed that eight variables were significant single predictors of GHQ-12 “case-level” distress: Emotional Uncertainty, total satisfaction with supports, age, marital status (married or living with a partner/not married or

living with a partner), medical conditions, psychiatric history, psychiatric hospitalisation and Cognitive Uncertainty (Table 4.6).

Table 4.6: Significant single predictors of GHQ-12 “case-level” distress

Variable	P	Odds ratio	95% CI
<i>Emotional Uncertainty</i> ^a	.00	1.11	1.07 to 1.16
<i>Total satisfaction with supports</i>	.01	.93	.88 to .98
Age	.03	1.05	1.01 to 1.10
Marital status	.02	.43	.22 to .86
Medical conditions	.00	2.52	1.39 to 4.59
Psychiatric history	.00	3.05	1.68 to 5.51
Psychiatric hospitalisation	.03	4.92	1.14 to 21.19
Cognitive Uncertainty	.03	1.05	1.01 to 1.09

^a *italics indicates a hypothesised variable*

All of the variables found to be significant single predictors of GHQ-12 “case-level” distress were entered into a multiple logistic regression model. Three variables were initially found to make a significant contribution to the prediction of GHQ-12 “case-level” distress: psychiatric history, age and Emotional Uncertainty. However, the 95% confidence intervals for age (1.00 to 1.13) included an odds ratio of one, which indicated there could be no change in odds if the model was extrapolated to a wider population. A further multiple regression analysis was carried out only entering the remaining two variables, which were both retained in the model (Table 4.7).

Table 4.7: Multiple logistic regression to predict GHQ-12 “case-level” distress (N = 239)

Nagelkerke R ² ^c	P ^c	Significant variables	Regression coefficient ^a	SE	df	P	Odds ratio	95% CI
.22	.00	Psychiatric history	.78	.33	1	.02	2.17	1.13 to 4.16
		<i>Emotional Uncertainty</i> ^b	.10	.02	1	.00	1.11	1.06 to 1.15

^a unstandardised

^b *italics indicates a hypothesised variable*

^c value for model

The odds of exhibiting GHQ-12 “case-level” distress:

- increases by 2.17 when a woman has a psychiatric history relative to if she has no psychiatric history.
- increases by 1.11 for each point increase in the Emotional Uncertainty subscale score.

For example the odds of exhibiting GHQ-12 “case-level” distress for a woman who has no psychiatric history and has an:

- Emotional Uncertainty score of 20 = 0.08
- Emotional Uncertainty score of 50 = 1.50

The model accounted for 22% of the “variation” in GHQ-12 “case-level” distress ($p < 0.00$) and correctly classified 78% of participants (29%; $n = 18$ cases/ 96%; $n = 168$ noncases).

4.9.12b *Predicting worry about developing breast cancer anytime now*

Four variables were shown by univariate analyses to be significant single predictors of responses to the item regarding worry about developing breast cancer anytime now (worried/not worried): perceived likelihood of developing breast cancer (unlikely/likely), Emotional Uncertainty, Monitoring and somatic symptoms (Table 4.8).

Table 4.8: Significant single predictors of worry about developing breast cancer anytime now

Variable	P	Odds ratio	95% CI
<i>Perceived likelihood of developing breast cancer^a</i>	.00	3.01	1.58 to 5.74
<i>Emotional Uncertainty</i>	.00	1.06	1.02 to 1.09
<i>Monitoring</i>	.01	1.26	1.07 to 1.48
<i>Somatic symptoms</i>	.04	1.15	1.01 to 1.32

^a *italics indicates a hypothesised variable*

All of the variables found to be significant single predictors of responses to the item regarding worry about developing breast cancer anytime now were entered into a multiple logistic regression model. Two variables made a significant contribution to the prediction of responses to this item: perceived likelihood of developing breast cancer and Emotional Uncertainty (Table 4.9).

Table 4.9: Multiple logistic regression to predict worry about developing breast cancer anytime now (N = 229)

Nagelkerke R ² ^c	P ^c	Significant variables	Regression coefficient ^a	SE	df	P	Odds ratio	95% CI
.13	.00	<i>Perceived likelihood of developing breast cancer</i> ^b	1.18	.35	1	.00	3.24	1.64 to 6.40
		<i>Emotional Uncertainty</i>	.06	.02	1	.00	1.06	1.02 to 1.10

^a unstandardised

^b *italics indicates a hypothesised variable*

^c value for model

The odds of being worried about developing breast cancer anytime now:

- increases by 3.24 when a woman perceives her risk of breast cancer as likely rather than unlikely.
- increases by 1.06 for each point increase in the Emotional Uncertainty subscale score.

For example the odds of being worried about developing breast cancer anytime now for a woman who feels she is likely to ever develop breast cancer and has an:

- Emotional Uncertainty score of 20 = 1.80
- Emotional Uncertainty score of 50 = 10.55

The model accounted for 13% of the “variation” in worry about developing breast cancer anytime now ($p < 0.00$) and correctly classified 67% of participants (21%; $n = 17$ worried/91%; $n = 136$ not worried).

4.9.12c Predicting worry about developing breast cancer in the future

Univariate analyses revealed three significant single predictors of responses to the item regarding worry about developing breast cancer in the future (worried/not worried): perceived likelihood of developing breast cancer (unlikely/likely), Emotional Uncertainty and Monitoring (Table 4.10).

Table 4.10: Significant single predictors of worry about developing breast cancer in the future

Variable	P	Odds ratio	95% CI
<i>Perceived likelihood of developing breast cancer</i> ^a	.00	2.89	1.65 to 5.09
<i>Emotional Uncertainty</i>	.00	1.08	1.03 to 1.12
<i>Monitoring</i>	.01	1.25	1.07 to 1.48

^a *italics indicates a hypothesised variable*

These three variables were entered into a multiple logistic regression model and all were shown to make a significant contribution to the prediction of responses to the item regarding worry about developing breast cancer in the future (Table 4.11).

Table 4.11: Multiple logistic regression to predict worry about developing breast cancer in the future (N = 233)

Nagelkerke R ² ^c	P ^c	Significant variables	Regression coefficient ^a	SE	df	P	Odds ratio	95% CI
.18	.00	<i>Perceived likelihood of developing breast cancer</i> ^b	1.07	.30	1	.00	2.91	1.60 to 5.28
		<i>Monitoring</i>	.21	.09	1	.02	1.24	1.04 to 1.48
		<i>Emotional Uncertainty</i>	.06	.02	1	.00	1.07	1.02 to 1.11

^a unstandardised

^b *italics indicates a hypothesised variable*

^c value for model

The odds of being worried about developing breast cancer in the future:

- increases by 2.91 when a woman perceives her risk of breast cancer as likely rather than unlikely.
- increases by 1.24 for each point increase in the Monitoring subscale score.
- increases by 1.07 for each point increase in the Emotional Uncertainty subscale score.

For example, the odds of being worried about developing breast cancer in the future for a woman who feels she is likely ever to develop breast cancer:

- has a Monitoring score of 0 and an Emotional Uncertainty score of 31 = 2.91
- has a Monitoring score of 8 and an Emotional Uncertainty score of 31 = 16.10
- has a Monitoring score of 4 and an Emotional Uncertainty score of 20 = 3.38
- has a Monitoring score of 4 and an Emotional Uncertainty score of 50 = 23.08

The model accounted for 18% of the “variation” in worry about developing breast cancer in the future ($p < 0.00$) and correctly classified 68% of participants (84%; $n = 117$ worried/45%; $n = 42$ not worried).

4.9.12d Predicting worry about dying from breast cancer and leaving their children

Univariate analyses showed four significant single predictors of responses to the item regarding worry about dying from breast cancer and leaving their children (worried/not worried): perceived likelihood of developing breast cancer (unlikely/likely), Emotional Uncertainty, Monitoring and age (Table 4.12).

Table 4.12: Significant single predictors of worry about dying from breast cancer and leaving their children

Variable	P	Odds ratio	95% CI
<i>Perceived likelihood of developing breast cancer^a</i>	.01	2.36	1.22 to 4.56
<i>Emotional Uncertainty</i>	.00	1.09	1.04 to 1.13
<i>Monitoring</i>	.01	1.29	1.07 to 1.55
<i>Age</i>	.02	.94	.90 to .99

^a *italics indicates a hypothesised variable*

All of these significant single predictors of responses to the item regarding worry about dying from breast cancer and leaving their children were entered into a multiple logistic regression model. The four variables entered were all shown to make a significant contribution to the prediction of responses to this item (Table 4.13).

Table 4.13: Multiple logistic regression to predict worry about dying from breast cancer and leaving their children (N = 186)

Nagelkerke R ² ^c	P ^c	Significant variables	Regression coefficient ^a	SE	df	P	Odds ratio	95% CI
.20	.00	<i>Perceived likelihood of developing breast cancer</i> ^b	.86	.37	1	.02	2.36	1.15 to 4.83
		<i>Monitoring</i>	.23	.10	1	.03	1.26	1.03 to 1.54
		<i>Emotional Uncertainty</i>	.07	.02	1	.00	1.08	1.03 to 1.13
		Age	-.06	.03	1	.03	.94	.89 to .99

^a unstandardised

^b *italics indicates a hypothesised variable*

^c value for model

The odds of being worried about dying from breast cancer and leaving their children:

- increases by 2.36 when a woman perceives her risk of breast cancer as likely rather than unlikely.
- increases by 1.26 for each point increase in the Monitoring subscale score.
- increases by 1.08 for each point increase in the Emotional Uncertainty subscale score.
- decreases by 0.94 for each additional year of a woman's age.

For example, the odds of being worried about dying from breast cancer and leaving their children for a woman who feels she is likely ever to develop breast cancer:

- is age 43, has a Monitoring score of 0 and an Emotional Uncertainty score of 31 = 1.79
- is age 43, has a Monitoring score of 8 and an Emotional Uncertainty score of 31 = 11.19
- is age 43, has a Monitoring score of 4 and an Emotional Uncertainty score of 20 = 2.01
- is age 43, has a Monitoring score of 4 and an Emotional Uncertainty score of 50

- = 17.92
- is age 30, has a Monitoring score of 4 and an Emotional Uncertainty score of 31
= 9.64
- is age 60, has a Monitoring score of 4 and an Emotional Uncertainty score of 31
= 1.64

The model accounted for 20% of the “variation” in worry about dying from breast cancer and leaving their children ($p < 0.00$) and correctly classified 66% of participants (48%; $n = 37$ worried/78%; $n = 85$ not worried).

4.9.12e *Predicting worry about their children’s risk of developing breast cancer*

Four variables were shown by univariate analyses to be significant single predictors of responses to the item regarding worry about their children’s risk of developing breast cancer (worried/not worried): Emotional Uncertainty, psychiatric history, number of daughters and GHQ-12 “case-level” distress (Table 4.14).

Table 4.14: Significant single predictors of worry about their children’s risk of developing breast cancer

Variable	P	Odds ratio	95% CI
<i>Emotional Uncertainty</i> ^a	.05	1.04	1.00 to 1.08
Psychiatric history	.00	2.60	1.40 to 4.82
Number of daughters	.00	2.22	1.48 to 3.34
GHQ-12 “case-level” distress	.02	2.26	1.17 to 4.37

^a *italics indicates a hypothesised variable*

All of these variables were entered into a multiple logistic regression model to determine the best prediction of responses to the item regarding worry about their children’s risk of developing breast cancer. Two variables made a significant contribution to the prediction of responses to this item (Table 4.15).

Table 4.15: Multiple logistic regression to predict worry about their children's risk of developing breast cancer (N = 188)

Nagelkerke R ² ^b	P ^b	Significant variables	Regression coefficient ^a	SE	df	P	Odds ratio	95% CI
.19	.00	Psychiatric history	1.16	.34	1	.00	3.18	1.62 to 6.23
		Number of Daughters	.95	.23	1	.00	2.58	1.65 to 4.02

^a unstandardised

^b value for model

The odds of being worried about their children's risk of developing breast cancer:

- increases by 3.18 when a woman has a psychiatric history relative to no psychiatric history.
- increases by 2.58 for each additional daughter.

For example, the odds of being worried about their children's risk of developing breast cancer for a woman with no psychiatric history and:

- 1 daughter = 0.62
- 3 daughters = 5.15

The model accounted for 19% of the "variation" in worry about their children's risk of developing breast cancer ($p < 0.00$) and correctly classified 65% of participants (54%; $n = 48$ worried/75%; $n = 74$ not worried).

4.9.12f *Predicting intrusive thoughts about breast cancer risk*

Four variables were found to be significant single predictors of scores on the Intrusion subscale of the IES on univariate analyses: Emotional Uncertainty, marital status (married or living with a partner/not married or living with a partner), education to age 16 (education to age 16 only/education after age 16) and Blunting (Table 4.16). These variables were subsequently entered into a multiple linear regression model.

Table 4.16: Significant single predictors of scores on the Intrusion subscale of the IES

Variable	Regression coefficient ^a	t	P	95% CI
<i>Emotional Uncertainty</i> ^b	.38	4.01	.00	.15 to .43
Marital status	-.28	-2.83	.01	-6.92 to -1.22
Education: to age 16	.33	3.40	.00	1.62 to 6.16
Blunting	-.29	-2.97	.00	-2.05 to -.41

^a standardised (Beta)

^b italics indicates a hypothesised variable

Two variables made a significant contribution to the prediction of scores on the Intrusion subscale: education to age 16 and Emotional Uncertainty (Table 4.17).

Table 4.17: Multiple linear regression to predict scores on the Intrusion subscale of the IES (N = 94)

Adjusted R ² ^b	P ^b	Significant variables	Regression coefficient ^a	SE	t	P	95% CI
.12	.00	Education: to age 16	3.29	1.11	2.97	.00	1.09 to 5.50
		<i>Emotional Uncertainty</i>	.17	.07	2.40	.02	.03 to .31

^a unstandardised

^b value for model

Higher scores on the Intrusion subscale were predicted by being educated to age 16 only and having higher scores on the Emotional Uncertainty subscale. For example, predicted scores on the Intrusion subscale for a woman who has been:

- educated to age 16 only and has an Emotional Uncertainty score of 31 = 8.69
- educated after age 16 and has an Emotional Uncertainty score of 31 = 5.40
- educated to age 16 only and has an Emotional Uncertainty score of 20 = 6.82
- educated to age 16 only and has an Emotional Uncertainty score of 50 = 11.92

The model accounted for 12% of the variance in Intrusion subscale scores (p = .00).

4.9.12g Predicting avoidant thoughts about breast cancer risk

Univariate analyses showed that four variables were significant single predictors of scores on the Avoidance subscale of the IES: Emotional Uncertainty, marital status (married or living with a partner/not married or living with a partner), education: to age 16 (education to age 16 only/education after age 16) and education: university graduate (university graduate/not) (Table 4.18). These variables were subsequently entered into a multiple linear regression model.

Table 4.18: Significant single predictors of scores on the Avoidance subscale of the IES

Variable	Regression coefficient ^a	t	P	95% CI
<i>Emotional Uncertainty</i> ^b	.23	2.31	.02	.03 to .43
Marital status	-.38	-4.04	.00	-10.77 to -3.68
Education: to age 16	.27	2.73	.01	1.14 to 7.25
Education: university graduate	-.22	-2.20	.03	-6.85 to -.34

^a standardised (Beta)

^b italics indicates a hypothesised variable

Marital status and education to age 16 made a significant contribution to scores on the Avoidance subscale (Table 4.19).

Table 4.19: Multiple linear regression to predict scores on the Avoidance subscale of the IES (N = 94)

Adjusted R ² ^b	P ^b	Significant variables	Regression coefficient ^a	SE	t	P	95% CI
.30	.00	Marital status	-8.06	1.54	-5.25	.00	-11.11 to -5.01
		Education: to age 16	5.66	1.29	4.38	.00	3.09 to 8.22

^a unstandardised

^b value for model

Higher scores on the Avoidance subscale were predicted by not being married or living with partner and being educated to age 16 only. For example, predicted scores on the Avoidance subscale for a woman who is:

- married or living with a partner and has been educated to age 16 only = 12.39
- not married or living with a partner and has been educated to age 16 only = 20.45
- married or living with a partner and has been educated after age 16 = 6.73
- not married or living with a partner and has been educated after age 16 = 14.79

The model accounted for 30% of the variance in Avoidance subscale scores ($p < .00$).

4.9.12h Predicting total Impact of Event Scale (IES) score

Six variables were found to be significant single predictors of total IES score: Emotional Uncertainty, marital status (married or living with a partner/not married or living with a partner), education to age 16 (education to age 16 only/education after age 16), education: university graduate (university graduate/not), occupation (employed/not employed) and Blunting (Table 4.20). These variables were subsequently entered into a multiple linear regression model.

Table 4.20: Significant single predictors of total IES score

Variable	Regression coefficient ^a	t	P	95% CI
<i>Emotional Uncertainty</i> ^b	.35	3.59	.00	.25 to .86
Marital status	-.37	-3.78	.00	-16.72 to -5.21
Education: to age 16	.34	3.53	.00	3.62 to 12.92
Education: university graduate	-.21	-2.09	.04	-10.36 to -.26
Occupation	-.21	-2.13	.04	-14.40 to -.49
Blunting	-.27	-2.64	.01	-4.30 to -.61

^a standardised (Beta)

^b italics indicates a hypothesised variable

Two variables made a significant contribution to the prediction of the total IES score: education to age 16 and marital status (Table 4.21).

Table 4.21: Multiple linear regression to predict total IES score (N = 91)

Adjusted R ² ^b	P ^b	Significant variables	Regression coefficient ^a	SE	t	P	95% CI
.18	.00	Education: to age 16	8.15	2.24	3.64	.00	3.70 to 12.61
		Marital status	-9.28	2.69	-3.45	.00	-14.62 to -3.93

^a unstandardised

^b value for model

Higher total IES scores were predicted by being educated to age 16 only and not being married or living with a partner. For example, predicted scores on total IES for a woman who has been:

- educated to age 16 only and is married or living with a partner = 21.11
- educated after age 16 and is married or living with a partner = 12.96
- educated to age 16 only and is not married or living with a partner = 30.39
- educated after age 16 and is not married or living with a partner = 22.24

The model accounted for 18% of the variance in total IES scores ($p < .00$).

4.9.12i Summary of results investigating psychological distress

Table 4.22 lists the variables that formed the best predictive models for each of the psychological distress variables.

Table 4.22: Summary of results investigating psychological distress

Psychological distress variable	Predictor
GHQ-12 “case-level” distress	Psychiatric history
	<i>Emotional Uncertainty coping style</i> ^a
Worry about developing breast cancer anytime now	<i>Perceived likelihood of developing breast cancer</i>
	<i>Emotional Uncertainty coping style</i>
Worry about developing breast cancer in the future	<i>Perceived likelihood of developing breast cancer</i>
	<i>Monitoring coping style</i>
	<i>Emotional Uncertainty coping style</i>
Worry about dying from breast cancer and leaving their children	<i>Perceived likelihood of developing breast cancer</i>
	<i>Monitoring coping style</i>
	<i>Emotional Uncertainty coping style</i>
	Age
Worry about their children’s risk of developing breast cancer	Psychiatric history
	Number of daughters
Intrusive thoughts about breast cancer risk	Education to age 16
	<i>Emotional Uncertainty coping style</i>
Avoidant thoughts about breast cancer risk	Marital status
	Education to age 16
Total Intrusive and Avoidant thoughts about breast cancer risk	Education to age 16
	Marital status

^a *italics indicates a hypothesised variable*

4.10 Discussion

4.10.1 Participants

The participation rate for the study was good (69%). The participants were representative of the 410 women who met the initial eligibility criteria in terms of age and number of years they had been attending the familial breast cancer clinic.

The vast majority of participants were of white ethnicity (only one woman was of non-white ethnicity). This reflects the predominantly white population in Scotland where in 1999 only 1.6% were of an ethnic minority background (Scottish Executive, 2002).

The participants in this study were also highly educated with over half being educated after age 18. Similar findings have been shown in other studies that have

recruited participants from the same familial breast cancer clinic (i.e. Rees, 2000, Personal communication; Cull et al, 1998), from other U.K clinics (e.g. Brain et al, 1999) and clinics internationally (e.g. Meiser et al., 2000, 2001b; Rimer et al., 1996). Indeed, a higher educational level has been shown to predict participation in a trial of breast cancer genetic risk counselling (Rimer et al., 1996). This tendency for breast cancer genetic risk counselling to attract highly educated women poses a potential problem that needs to be addressed by familial breast cancer clinics. Greater focus should perhaps be given to investigating effective ways of promoting attendance among less educated women and exploring their needs for information and support which are likely to be different from the highly-educated sample in this study.

Participants and non-participants could only be compared on a limited number of variables. It was not possible to ascertain whether the sample described here was biased with respect to variables such as psychological distress and coping style. It is likely that more distressed women chose not to participate in the study, particularly if they had a blunting coping style or were avoidant of breast cancer cues. However, a range of levels of general psychological and breast-cancer-specific distress were represented among participants.

4.10.2 Were the study aims met and hypotheses supported?

Aim 1: To assess the prevalence of general psychological morbidity (in terms of GHQ- 12 probable psychiatric “caseness”) in women living with an increased risk of breast cancer.

Twenty-six percent of participants exhibited “case-level” distress using a threshold of three points or more on the GHQ-12.

The prevalence of probable psychiatric morbidity obtained in this study is lower than that obtained in general population samples using the same measure and threshold (i.e. May, 1992; Plummer et al., 2000; Weich et al., 2001). However, these samples may not be comparable to the participants in the present study on a number of factors including age, gender and social deprivation. Although age has not been shown to have a strong influence on GHQ score, some studies have found that scores in women have a tendency to decrease with age (Goldberg & Williams, 1991). There is evidence that the prevalence of GHQ “case-level” distress is higher among women than men (Goldberg & Williams, 1991). In terms of social deprivation, there is limited evidence that greater prevalence is found in lower social classes and urban populations, but strong evidence of higher prevalence in the unemployed (Goldberg

& Williams, 1991). In addition, the fact that in two of these studies (i.e. May, 1992; Plummer et al., 2000) the participants were attending their general practice at the time of assessment, may have increased their levels of distress.

The prevalence of probable psychiatric morbidity is similar to that observed using the same measure and threshold in a sample of 249 women 12 months after genetic risk counselling (Watson et al., 1999) and is slightly lower than that obtained in a sample of 91 women six months after breast cancer genetic risk counselling (Watson et al., 1998). Similar results have been obtained in women attending for breast cancer genetic risk counselling using the GHQ-30 (i.e. Rees, 2000, Personal communication; Cull et al, 1998, 1999) where about one third of each sample exhibited "case-level" distress. This suggests that the prevalence of general psychological morbidity is similar in women who have been attending a familial breast cancer clinic for several years as in women who have recently attended breast cancer genetic risk counselling.

Aim 2: To assess the psychological status of women living with an increased risk of breast cancer in terms of general psychological distress (somatic symptoms) and breast cancer-specific distress (intrusive and avoidant thoughts about breast cancer risk and worry about breast cancer risk-related issues)

The extent to which participants reported experiencing somatic symptoms (10% scored at least five points out of seven) was comparable to Hopwood et al.'s findings using the same GHQ-28 subscale in women three months after breast cancer genetic risk counselling where 12% scored at least five points (Hopwood et al., 1998). Forty six percent of participants scored at least one point which is a slightly higher proportion than that reported for British women in the general population three months after receiving routine breast cancer screening (34%) (Ellman et al., 1989). However, the mean age of that sample was 53.9 years compared to 43.4 years in the present study. Differences in the age of the samples could help to account for differences in the results regarding somatic symptoms, given the evidence of an effect of age on GHQ scores. The results of our previous telephone focus group study suggest that women living with an increased risk of breast cancer may have an increased awareness of bodily symptoms as they are well informed about breast symptoms and are likely to have witnessed the symptoms of other relatives affected by breast cancer: "You have a heightened awareness of the possibility of breast cancer and you're always watching".

There was evidence that the minority of women (44%) who had thought about the risk of breast cancer in the past week and had therefore completed the Impact of Event Scale were different from the women who had not completed the scale in terms of coping style, somatic symptoms, appraisal and worry about breast cancer-risk related issues. The results suggest that these women were more likely to have higher scores on the Monitoring subscale, Emotional Uncertainty subscale and somatic symptoms subscale, were more likely to perceive themselves as likely to develop breast cancer and to worry about breast cancer risk-related issues.

As far as intrusive and avoidant thoughts about breast cancer risk were concerned, the results were similar to other studies of women attending a familial breast cancer clinic (e.g. Rees, 2000, Personal communication; Watson et al., 1999) and substantially higher than in women in the general population (e.g. Lloyd et al., 1996; Rees, 2000, Personal communication). Although these results imply that this type of breast cancer-specific distress does not generally decrease the longer women attend a familial breast cancer clinic, such intrusive and avoidant thoughts may only be a problem for a subset of women (less than half of participants indicated that they had thought about the risk of breast cancer in the past week).

Worries about issues relating to breast cancer risk were common with a large proportion of women (73%) being worried in the past week by at least one of the issues related to breast cancer risk that were listed. By far the most common worry was about developing breast cancer in the future, which represents a realistic concern for these women.

Aim 3: To assess the prevalence of information needs and preferences in women living with an increased risk of breast cancer.

The results confirmed the findings of the telephone focus group study as a common need for up-to-date information related to familial risk of breast cancer was identified. Although the most frequently requested topics were on scientific subjects such as breast cancer genetics and genetic testing, a large proportion of participants also expressed a need for psychosocial topics such as maintaining a healthy lifestyle and stress management.

Over 90% of participants indicated that they would be interested in receiving at least one of the 11 topics of information listed and at least one of the four information formats listed. However, in contrast to the results of the telephone focus group study where written materials were regarded as supplementary to a group meeting, in this study there was an overall preference (85%) for the information to be

presented in a written format. The variation in preferences may reflect differences in the samples of the two studies. Given that the telephone focus group participants were a small group of women who volunteered to take part in a telephone discussion group, they may be more likely to prefer receiving information in an interactive environment such as a group meeting.

Aim 4: To investigate the impact of appraisal, coping style, social support and breast cancer cues on general psychological distress (GHQ-12 “case-level” distress) and breast cancer-specific distress (intrusive and avoidant thoughts about breast cancer risk and worry about breast cancer risk-related issues) in women living with an increased risk of breast cancer.

This aim was met by testing the study hypotheses through univariate analyses. Further multivariate analyses then identified the combination of variables that best predicted general psychological and breast cancer-specific distress.

Hypothesis 1a: Women who perceive themselves to be at a greater risk of developing breast cancer will show greater levels of psychological distress than women who perceive themselves to be at a lower risk.

There was a substantial amount of support for this hypothesis: perceiving your risk of developing breast cancer as likely (rather than unlikely) independently predicted being worried about a number of breast cancer-risk-related issues (i.e. developing breast cancer anytime now, developing breast cancer in the future, dying from breast cancer and leaving their children). For example, a woman was three times more likely to be worried about developing breast cancer now if she perceived herself as likely rather than unlikely to develop breast cancer.

Previous research in women with a family history of breast cancer has shown that greater perceived likelihood of developing breast cancer in the future is associated with increased general psychological and breast cancer-specific distress (Erblich et al., 2000).

Hypothesis 1b: Women who perceive themselves to have less control over their risk of developing breast cancer will show greater levels of psychological distress than women who perceive themselves to have greater control over their risk.

There was no evidence that perceiving less control over developing breast cancer was related to greater general psychological or breast cancer-specific distress. These findings are in contrast to previous research. For example, Cull et al. (2001a) found that having an internal locus of control regarding your health (i.e. perceiving control of your health through your own behaviour) was significantly associated with GHQ-30 “case-level” distress in women attending a familial ovarian cancer clinic. High perceptions of control over breast cancer risk have previously been found to be predictive of low levels of general psychological distress and fewer intrusive thoughts in women with a family history of breast or ovarian cancer (Audrain et al., 1997).

The lack of support for this hypothesis from the present study could be due to the fact that the participants had been living with the knowledge of their increased risk of breast cancer for several years. During this time a relationship between perceived control and psychological distress may become less pronounced as the women gain more experience of living with an increased risk of breast cancer and perhaps learn to minimise the psychological impact of their beliefs.

Hypothesis 2a: Women with a high Monitoring coping style will show greater psychological distress than women with a low Monitoring coping style.

A higher score on the Monitoring subscale was found independently to predict being worried about: developing breast cancer anytime now, developing breast cancer in the future and dying from breast cancer and leaving their children. As expected, those women who have a tendency to scan for cues related a specific threat (Miller 1987), are likely to experience more worry about breast cancer risk-related issues. Likewise, Wardle et al. (1995) have shown that Monitoring made an independent contribution to the prediction of cancer worry in women with a family history of ovarian cancer where greater Monitoring predicted greater worry.

Hypothesis 2b: Women with a high Monitoring coping style will show greater intrusive thoughts about breast cancer than women with a low Monitoring coping style.

There was no evidence to support the hypothesis as Monitoring was not found to be predictive of intrusive thoughts about breast cancer risk. In contrast to the present findings, Schwartz et al. (1995) found that a high level of Monitoring was related to greater intrusive thoughts about breast cancer in women at increased risk of

ovarian cancer. However, in the current study a higher score on the Blunting subscale was found to independently predict fewer intrusive thoughts about breast cancer risk and a smaller total IES score. It does seem plausible that women who tend to cope with threat-related cues by distraction (Miller 1987) would experience less intrusive thoughts about their risk of breast cancer. This finding supports Myers & Derakshan (2000), who suggest that Monitoring and Blunting remain separate constructs (i.e. low Monitoring and high Blunting are not equivalent) which should be analysed as such (i.e. two subscale scores rather than a total score).

Hypothesis 2c: Women with a high score on Emotional Uncertainty will show greater psychological distress than women with a low score on Emotional Uncertainty.

Higher scores on the Emotional Uncertainty subscale were shown independently to predict GHQ-12 case-level distress, being worried about a number of breast cancer risk-related issues (i.e. developing breast cancer anytime now, developing breast cancer in the future, dying from breast cancer and leaving their children, their children's risk of developing breast cancer), intrusive and avoidant thoughts about breast cancer risk. The 95% confidence intervals for worry about their children's risk of developing breast cancer included an odds ratio of 1, which indicates this result should be interpreted with caution. However, the results still provide a large amount of support for the hypothesis in terms of the other measures of psychological distress.

These findings suggest that women who have a tendency to respond to uncertain situations in emotional ways (e.g. anger, anxiety, depression) are more likely to experience negative psychological effects of living with an increased risk of breast cancer. Emotional Uncertainty has been shown to be associated with "a lack of detachment from stressful situations" and is suggested to represent a maladaptive style of coping with uncertain situations through becoming distressed (Greco & Roger, 2001). Greater distress and uncertainty have been reported during an experimental manipulation of uncertainty by individuals scoring high on the Emotional Uncertainty subscale (Greco & Roger, 2001). As coping style may not be amenable to intervention, it may be pertinent for future research to investigate the provision of additional psychological support to those women who score highly on the Emotional Uncertainty subscale.

Hypothesis 3: Women who are less satisfied with their social supports will show greater psychological distress than women with greater satisfaction with their social supports.

There was some support for this hypothesis as lower total satisfaction with social supports was independently found to predict GHQ-12 “case-level” distress. However, the results did not show any relationship between total satisfaction with social supports and breast cancer-specific distress. There are several possible explanations for these results. Even women with good social support may not be completely protected from the potential distress associated with being at increased risk of breast cancer. An alternative explanation may be due the nature of the instrument used to assess social support. The SSQ-6 assessed social support in general and did not specifically refer to support coping with particular difficulties such as those associated with having an increased risk of breast cancer (e.g. support when waiting for the results of a mammogram). Future studies could develop a measure to assess such specific social support and investigate the impact of this support on breast cancer-specific distress.

Hypothesis 4: Women who are approaching the age when their mother was diagnosed with breast cancer will show greater psychological distress than women who are much younger or older than their mother at diagnosis.

The results did not provide any evidence to support the hypothesis. The difference between age of the participant’s mother at diagnosis of breast cancer and the current age of the participant herself was not related to the participant’s levels of general psychological or breast cancer-specific distress. This is in contrast to the qualitative findings of the telephone focus group study where participants commonly described an increase in anxiety as they approached the age at which an affected relative had been diagnosed with breast cancer (e.g. “My mum was diagnosed at 40 but she didn’t die till she was 42 so I’ll be 40 this year... it’s coming over me like a big shadow”). Several women also described their anxieties gradually being alleviated as they passed this age. Differences in chronic levels of distress may have masked any changes in distress due to this breast cancer cue. Therefore, a longitudinal study may be more appropriate to investigate levels of chronic distress and changes in distress as a woman approaches, reaches and passes the same age when her mother was diagnosed with breast cancer.

4.10.3 Predicting “case-level” distress

The factors identified as being important in predicting GHQ-12 “case-level” distress were having a psychiatric history and having tendency to cope with uncertain situations in emotional ways (Emotional Uncertainty coping style was already shown to be important in univariate analyses).

These results support the findings of Cull et al. (2001b). They found that cancer patients who reported a past psychiatric history were twice as likely to be identified as cases on clinical interview than patients without such a history. Hopwood et al. (1998) have also shown that significantly more women who had a self-reported psychiatric history were confirmed to have a psychiatric disorder three months after attending breast cancer genetic risk counselling than women who had not reported such a history.

4.10.4 Predicting intrusive and avoidant thoughts about breast cancer risk

Levels of intrusive and avoidant thoughts about breast cancer risk (including total IES score) were shown to be predicted by different combinations of three variables: being educated to age 16 only, being unmarried or not living with a partner and having tendency to cope with uncertain situations in emotional ways (Emotional Uncertainty coping style was already shown to be important in univariate analyses).

Women who are less well educated may be not be well informed about relevant breast cancer risk-related issues. Therefore they may experience unresolved uncertainty surrounding these issues, which may increase their levels of breast cancer-specific distress. Baider et al. (1999) found that being less well educated was related to greater intrusive thoughts about breast cancer amongst women with a family history of breast cancer who were attending an educational programme about the diagnosis and genetics of breast cancer.

The finding that being unmarried or not living with a partner was important in predicting greater avoidant thoughts and total IES score may reflect a lack of adequate social support in this group of women. However, total satisfaction with social supports was not found to be independently predictive of intrusive or avoidant thoughts about breast cancer risk. The SSQ-6 may be too general a measure of social support to be sensitive to detect support specific to coping with an increased risk of breast cancer. Research in women with a family history of breast or ovarian cancer has found that being married was related to lower levels of general psychological distress (i.e. Audrain et al., 1997; Baider et al., 1999).

4.10.5 Predicting worry about breast cancer risk-related issues

Three factors were found to be important in predicting worry about a number of breast cancer-risk related issues: perceiving your risk of developing breast cancer as likely (rather than unlikely), having tendency to cope with uncertain situations in emotional ways and having a Monitoring coping style. These findings were not surprising, given the support provided for the study hypotheses by univariate analyses.

Being younger was also important in predicting worry about dying from breast cancer and leaving their children. As younger women may be more likely to have young children than older women, it seems plausible that they would be more concerned about leaving their children at an age when they cannot look after themselves. This reflects the findings of the telephone focus group study where women with young children described a major concern about their children's ability to cope if they developed breast cancer which mirrored their own experience of losing their mothers at a very young age: "We were very small when my mother died and I'd hate to leave my children now so I think when you bring small ones into the equation that certainly worried me more".

As far as predicting worry about their children's risk of breast cancer, only two factors made an significant contribution: having a psychiatric history and having more daughters. It is not clear why having a psychiatric history was only important in predicting worry about other people. There was evidence from the telephone focus group study that having daughters was particularly linked to worry about their children's risk of breast cancer. This was commonly described by women with daughters: "I can cope with sort of having the gene or whatever but it suddenly dawned on me about my own two daughters...I can cope with it myself but I wonder about my children, maybe that's over the years I've thought that now".

4.11 Methodological issues

There were a number of methodological issues concerning the study that should be noted.

Due to the shortage of well-developed measures for some of the key constructs of the study (i.e. information needs and preferences, breast cancer cues, worry about breast cancer risk-related issues), a number of study-specific items were developed. Several methodological difficulties were experienced with some of these

items. One participant did not understand the term “prophylactic surgery” which was used in one of the information needs and preferences items. It became apparent during the course of the study that other ad hoc items were worded in a slightly ambiguous or unclear manner. For example, the response “alive but unwell” to the family history items concerning the status of relatives with breast cancer did not indicate if breast cancer was the cause of the ill-health. It may have been better to separate the two breast cancer cues items about waiting for/receiving the results of a mammography or breast biopsy into two parts, one referring to the results of a mammogram and the other to the results of a breast biopsy. In this way, a routine visit to the clinic may have been distinguished from an additional appointment. The item regarding worry about the frequency of their clinic appointments was confusing for some participants. It may have been clearer to use infrequency rather than frequency or to have asked participants if their worry was about too few or too many appointments. For some of the ad hoc items developed to assess breast cancer cues and information needs and preferences, there was a relatively large proportion of missing data. This may have been minimised if the responses were in a yes/no format rather than a checklist to endorse.

In addition to the methodological issues experienced with some of the ad hoc items, there were also problems with some of the standard measures. Although the Uncertainty Response Scale was shown to be a useful measure of coping style in this group of women, the use of “discern” in one of the items was found to be confusing by one participant. There was a substantial amount of missing data on the SSQ-6, which may have been due to the large amount and format of the information requested by this measure (several participants commented that this measure was difficult to complete).

Inconsistencies were apparent between completing the Impact of Event Scale (IES) opt-out box (i.e. indicating they had not thought about the risk of breast cancer in the past week), being worried about a breast cancer risk-related issue and having experienced a breast cancer cue in the past week. Of the 138 women who completed the IES opt-out box, a substantial proportion indicated that they had been worried in the past week about a breast cancer risk-related issue (e.g. 35% had been worried about developing breast cancer in the future, 23% had been worried about their children’s risk of developing breast cancer), or indicated that they had experienced a breast cancer cue in the past week (e.g. 33% had experienced a media report about breast cancer, 38% had examined their breasts). These findings suggest that opting-out of completing the IES does not necessarily indicate that an individual has not thought about their breast cancer risk in the past week as it could reasonably be

assumed that worry about a breast cancer-risk related issue must have involved some degree of thought about breast cancer risk. Alternatively, participants may not have read or responded appropriately to the time-frame specified by the questions. Further investigations on the use and validity of the IES opt-out box would be required.

There were a number of limitations in the models produced by multiple logistic regression. The amount of “variation” in psychological distress accounted for by the models ranged from 13-22%. The proportion of participants correctly classified as exhibiting “case-level” distress/being worried about a breast cancer risk-related issue or not ranged from 65-78% between models. The models generally correctly classified greater proportions of women who did not exhibit “case-level” distress or who weren’t worried than those who showed “case-level” distress or who were worried. This is reflected in the fact that all of the deviance plots of the multiple logistic regression models did not appear to be normally distributed which would indicate that there were a number of women for which the models didn’t fit very well. The classification plots also highlighted women with high probabilities of being classified in the incorrect group (e.g. as worried instead of not worried). The model of worry about developing breast cancer anytime now produced a significant Hosmer & Lemeshow test ($p = .015$) which indicates that the model did not fit the data very well. Only 21% of the worried women were correctly classified. All of these results suggest that there was substantial room for improvement in the predictive value of the models produced, particularly for distressed or worried women whom it would be important to accurately identify.

Likewise the multiple linear regression models may have several methodological limitations. As 138 women ticked IES opt-out box indicating that they had not thought about the risk of breast cancer in the past week, the sample included in these models was about one third of total sample. In addition, the multiple linear regression models did not account for the majority (12-30%) of the variance in Intrusion, Avoidance and total IES score. Given these potential biases and limitations, the models should be interpreted with caution.

The participants may have experienced additional breast cancer cues during the study that may have affected their responses to the questionnaire. National breast cancer awareness month took place during the study period (22% of participants completed their questionnaire during this month). Several women also commented that participating in the study had made a large impact on the amount they had thought about their breast cancer risk. Although this breast cancer cue is obviously not avoidable when conducting such a study, its potential influence on the results should be considered.

4.12 Study limitations

There were several limitations of the study in terms of the constructs that were investigated and the interpretation of the results.

Several factors that were likely to influence psychological distress were not investigated in the study.

Firstly, participants were originally asked to provide dates of their last and next scheduled appointment at the familial breast cancer clinic and to indicate if they had attended the clinic in the past week. A sample of these responses were compared and checked with the clinical case notes and were found to be unreliable. As it was outside the scope of this study to collect this data from 249 participant's case notes, the clinic appointment data were excluded from any analysis. Participants in the telephone focus group study described experiencing a period of heightened emotions as they approached and attended their routine appointment at the familial breast cancer clinic: "I tend to blank it out when I walk out of there (the familial breast cancer clinic) until a week before I'm due to go back again and I start to think about it during that week". Future studies could test the hypothesis that women who have either recently attended a familial breast cancer clinic or who are approaching the day of their next routine appointment will show greater psychological distress than women with a greater distance in time to their last or next appointment.

Secondly, the participants' accuracy of their perceived risk of developing breast cancer was not assessed in this study. There were two problems with the objective breast cancer risk estimates recorded for each participant on the clinical database: (1) they were in a different non-comparable format (i.e. percentages, categories, ranges) for different women; (2) they were recorded during genetic risk counselling several years previously and were not necessarily up-to-date. Therefore, without access to an accurate and comparable estimate of breast cancer risk, the participants' accuracy of their perceived risk in terms of under-, over- and correct estimates could not be assessed. In addition, participants' change in their perceived risk of breast cancer since first attending the clinic could not be compared to a possible change in their objective breast cancer risk (e.g. due to a change in their family history). A number of studies have investigated the relationship between accuracy of breast or ovarian cancer risk perception and psychological distress (e.g. Cull et al, 1998, 1999, 2001a; Hopwood et al., 1998, 2001; Watson et al., 1998, 1999). For example, Cull et al. (2001a) found that twice as many participants who overestimated their ovarian cancer susceptibility exhibited "case-level" general psychological distress than women who were under-estimators. First-time attendees

of breast cancer genetic risk counselling who over-estimate their risk of breast cancer were shown to be more likely to have frequent or constant worries about cancer than those women who under- or correctly estimated their risk (Watson et al., 1999).

Thirdly, one participant reported the effect of a recent bereavement on her questionnaire responses (her mother had died from oesophageal cancer during the study period). Experiencing a recent bereavement of a personally known relative from breast cancer has been found to be associated with greater general psychological distress in women attending a familial breast cancer clinic (Rees, 2000, Personal communication). There are sound theoretical explanations for the influence of personal experience of breast cancer in the family, including bereavements, on emotional and cognitive responses to personal risk of developing breast cancer (Rees et al., 2001).

Research has shown that a number of aspects of experiencing breast cancer in the family predict general psychological distress and cancer worry (Rees, 2000, Personal communication).

There were also limitations with the interpretation of results.

Although the items concerning worry about breast cancer-risk-related issues assessed the actual content of these worries, they did not indicate to what extent these worries interfered with their everyday life. The Cancer Worry Scale (original items: Lerman et al., 1991a, 1991b, 1993, 1994; 6-item scale: Watson et al., 1998) contains six items to assess the effect of worry about cancer on daily functioning in terms of its frequency and severity. The scale has now been subjected to thorough psychometric testing and has performed satisfactorily (i.e. Brain et al., 1999; Rees, 2000, Personal communication; Hopwood et al., 2001). It may be appropriate to use this scale in future research to investigate cancer-specific worry.

As this study was of a cross-sectional design, the results that demonstrate a relationship between a particular variable and psychological distress do not indicate a causal link between these variables. Therefore, further longitudinal research would be needed to investigate the causes of both general psychological distress and breast cancer-specific distress in this population. This would allow appropriate interventions to prevent or minimise psychological distress to be designed and evaluated.

4.13 Clinical implications and future research

This study of long-term attendees of a familial breast cancer clinic found a similar prevalence of “case-level” general psychological distress and similar levels of breast cancer-specific distress as shown in first-time attendees. A subset of women were shown to experience thoughts and worries about cancer which had a considerable detrimental impact on their daily lives. Further longitudinal research is needed to investigate the severity and persistence of these worries and to determine if there is a need for psychological help among these women. This would enable the development of appropriate psychological interventions to reduce severe distress in this group of women.

This study also highlighted the importance of a number of sociodemographic, appraisal, coping style and social support factors in predicting general psychological and breast cancer-specific distress. The exact role of these factors in causing distress warrants further research which would enable a greater understanding of the causes, prevention and reduction of distress in this group of women.

Participants expressed clear needs for up-to-date and reliable information on issues related to familial risk of breast cancer. These results informed both the content and format of a subsequent intervention designed to meet the needs of these women.

Chapter 5: The Development of a Psychoeducational Intervention for Women Living with an Increased Risk of Breast Cancer

5.1 Introduction

Research in cancer patients has linked poor provision of information with adverse psychological and physical outcomes (Thomas et al., 1999). This research has also shown that patient well-being can improve with the increased provision of information (Thomas et al., 1999). Many participants in the telephone focus group study (Chapter 3) found that being well informed on relevant issues had decreased their anxiety and assisted their decision-making: "...the more knowledge and information you have, the easier it is to cope with things and the more it helps you".

Little published information has been produced specifically for women with a family history of breast cancer. The information available to date includes leaflets and web pages about breast cancer genetics and genetic testing (e.g. National Cancer Institute, 1997), a book covering a number of issues relevant to women with a family history of breast cancer (i.e. Kelly, 2000) and a leaflet about familial breast/ovarian cancer for women who suspect they may be at increased risk of the disease (i.e. Cancer Research Campaign, 1999). This information, which predominantly targets American women and covers scientific issues related to familial breast cancer, has not been written specifically to address the needs of long-term attendees of a familial breast cancer clinic.

Of the variety of interventions in women with a family history of breast cancer involving information giving (e.g. Audrain et al., 1999; Cull et al., 1998; Espen et al., 2000; Gagnon et al., 1996; Kash et al., 1999; Lerman et al., 1996; Schwartz et al., 1998; Watson et al., 1998; Wellisch et al., 1999) only one has focussed on a purely written intervention. Gagnon et al. (1996) carried out a pilot randomised controlled trial of a series of newsletters as part of a larger longitudinal study. The newsletters aimed to improve accuracy of perceived risk of breast cancer, to decrease both general psychological and cancer-specific distress and to improve adherence to breast self-examination. Four consecutive issues of a written newsletter were sent to 41 American women who were attending breast cancer genetic risk counselling. These newsletters contained information and advice on breast cancer screening (clinical breast examination, mammography, breast self-examination), diet and cancer, breast cancer risk factors and genetic counselling. However, a

comparison of the newsletter group (n = 26) and control group (n = 23) showed no significant differences on the key outcomes post-intervention (about a month after the last issues of the newsletter had been received). The lack of evidence may be due to a number of methodological limitations of the study including: a lack of data about whether the newsletters were actually read, extensive media coverage on breast cancer during the study period (Gagnon et al., 1996) and the small sample size.

It is therefore evident that there is a lack of both published written information covering scientific and psychosocial issues and published psychoeducational interventions for British women who are long-term attendees of a familial breast cancer clinic.

5.2 Rationale

Like most familial breast cancer clinics in the U.K, the Ardmillan familial breast cancer clinic in the South East of Scotland does not routinely provide long-term attendees with education or psychosocial support. For these women, contact with the clinic is limited to routine appointments, which may be at least at yearly intervals. During these follow-up appointments, there is an opportunity to update a woman's family history and the appropriate breast cancer screening such as clinical breast examination or mammography is performed. Due to growing numbers of referrals to familial breast cancer clinics and hence pressures on the resources of staff time, these follow-up appointments are also likely to become shorter and less frequent. Therefore the opportunity at the clinic to be updated on relevant scientific developments or discuss psychosocial issues may be increasingly restricted. As one participant in the telephone focus group study expressed (Chapter 3): "I don't think I've been (to the clinic) for more than a year so I suppose I feel slightly out of touch with what's going on". There were also concerns expressed by clinicians that some of these women may not be receiving adequate information or support.

All of the 25 participants in the telephone focus group study (Chapter 3) of long-term attendees of the clinic highlighted at least one unmet need in terms of information or support related to their risk of breast cancer. Providing reliable information on topics related to familial breast cancer was seen to be an important addition to the existing clinical service: "I personally would like to maybe receive a newsletter or something...some sort of information or something that makes you think, well you know I'm not just going to be thought of once a year".

In the subsequent cross-sectional questionnaire study (Chapter 4) of 249 long-term attendees of the clinic, the results of the telephone focus group study regarding unmet needs were confirmed. A widespread need for up-to-date information related to familial risk of breast cancer was identified. The eight most popular topics of information requested were: breast cancer genetics (72%), research conducted at the familial breast cancer clinic (68%), genetic testing (67%), breast cancer treatment (63%), breast cancer screening (59%), healthy lifestyle (49%), stress management (41%) and hormone replacement therapy (41%). There was also a general preference for this information to be in a written form (84%) rather than group meetings with (21%) or without their families (40%) or telephone discussion groups (11%).

In terms of scientific information, it seems important to provide these women with up-to-date reliable information on issues about familial risk of breast cancer that may concern them. Given the scientific advances in this area in recent years, the information these women received when they initially attended for genetic risk counselling several years previously, may now be out of date. In addition, some of the information about breast cancer these women can access such as through the Internet may not necessarily be reliable or applicable to them. These women already live with the chronic uncertainty about whether or when they will develop breast cancer. If additional uncertainties could be clarified or resolved their burden would perhaps be reduced.

Long-term attendees of a familial breast cancer clinic are likely to vary in their ability to cope with uncertainty (Appleton et al., 2000). As breast cancer represents a realistic concern for these women, worry about their risk is understandable. However, a subset of these women may experience chronic distress, which adversely affects them in their everyday lives (Appleton et al., 2000). A recent review of self-help treatments has shown that written information can be beneficial for primary care patients suffering from anxiety or depressive disorders (Bower et al., 2001). Therefore, psychosocial or self-help information to help reduce worry is likely to be useful for those women who may be suffering from similar psychological disorders. Although these women commonly have relatives with breast cancer and family members who are also attending a familial breast cancer clinic, they do not necessarily gain emotional support for coping with their increased risk from these channels: "They (my sisters) say when they are going (to the clinic) but apart from that it's never, we don't discuss the risk and any anxieties that any of us have got - we should I don't know why we don't" (from the telephone focus group study, Chapter 3).

Given this evidence, a psychoeducational written intervention was developed to meet the needs of these women. It was designed both to update and augment the information these women previously received at the clinic. The written format would allow the information to be accessible as required thus providing an immediate source of advice.

5.3 Aim

The aim was to develop a psychoeducational written information pack for long-term attendees of a familial breast cancer clinic consisting of scientific and psychosocial information with the intention of 1) improving knowledge of scientific topics of information related to familial risk of breast cancer 2) reducing cancer worry.

5.4 Development

Figure 5 describes the 12 stages of developing the information pack.

A review of the literature on the development of patient information was carried out (1). This identified a number of recommendations for producing good quality patient health information (i.e. Ewles et al., 1985; Coulter et al., 1998; Centre for Health Information Quality, 1997, 1999, 2000; Plain English Campaign, 2001a & b). These guidelines informed the development procedure.

The structure of the information pack was based on the eight topics of information most often requested in the cross-sectional study (Chapter 4) (2). These were classified as six scientific topics and two psychosocial topics.

A multidisciplinary steering group chaired by a postgraduate health psychologist (S.A) was set up to develop the information pack (3). The group consisted of a specialist registrar in clinical genetics (S.G-M), a consultant clinical psychologist (A.C) and a consultant in clinical genetics (M.P). The lead writer for five of the scientific topics was S.G-M and S.A was the lead writer for the two psychosocial topics and remaining scientific topic (i.e. research conducted at the familial breast cancer clinic). Two additional topics were also devised to complement the main topics: a general introduction to breast cancer (lead writer S.G-M.) and a sources of information topic (lead writer S.A).

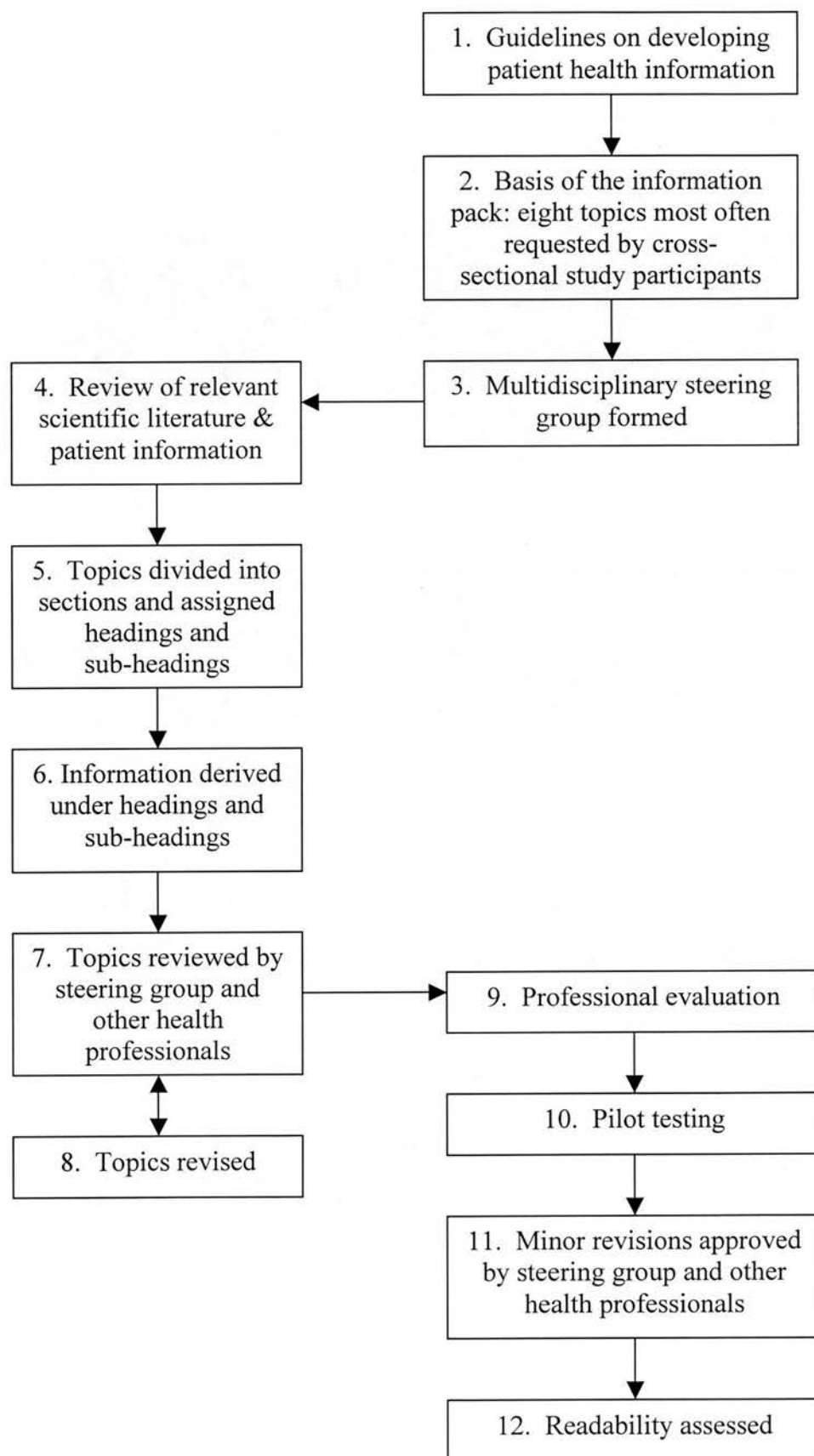


Figure 5: Stages of developing the information pack

A review of the current scientific literature and existing information resources (leaflets, web pages) for women with a family history of breast cancer (available internationally) was undertaken in order to identify areas in these topics where (4):

- Existing patient information was appropriate for this group of women.
- Existing patient information could be modified to be relevant for this group of women.
- No appropriate patient information existed but information from a journal article or book could be used if reworded.
- No relevant information existed in any form so it would have to be written from scratch.

Each topic was divided into sections under headings and sub-headings by the lead writers (5) (see Table 5.1 for examples). The information was derived from the current scientific literature and/or existing patient information resources and/or written from scratch. This information was then organised under the headings and sub-headings (6). In order to produce the topic summarising the scientific and psychosocial research conducted at the familial breast cancer clinic, S.A. collected and edited summaries of the studies from the appropriate researchers and organised them into a coherent topic.

Table 5.1: Examples of topic structure

Topic	Heading	Sub-heading
<i>Genetic testing</i>	What is genetic testing?	
	Who should be tested?	Women at moderate risk of breast cancer
		Women at high risk of breast cancer
	What do genetic test results mean?	
<i>Healthy lifestyle</i>	Lifestyle and the risk of breast cancer: what does the research show?	
	If there is no clear evidence that lifestyle causes breast cancer, why should I maintain a healthy lifestyle?	
	How can I maintain a healthy lifestyle?	Diet
		Vitamin and mineral supplements
		Alcohol
		Smoking
		Sun and sunbeds
		Exercise

The draft topics were circulated within the steering group and alterations suggested (7). The topics were then modified by the lead writers before being re-circulated within the steering group. The topics (except the research summary and sources of information) were also reviewed by another appropriate health professional (7) (introduction, breast cancer genetics and genetic testing were reviewed by a genetics associate and a consultant in clinical genetics; breast cancer screening, HRT and diagnosis and treatment of breast cancer were reviewed by a consultant breast surgeon; healthy lifestyle was reviewed by a consultant clinical psychologist and worry about breast cancer was reviewed by a health psychologist and consultant clinical psychologist). This process of reviewing and altering the topics was repeated until a satisfactory final draft of the information pack was produced (8).

The final draft of the information pack which contained 10 topics and three published leaflets was evaluated by health professionals (9) and subjected to pilot testing on women at increased risk of breast cancer (10). The three published leaflets were selected on their relevance, potential helpfulness, clarity, presentation and cost. Minor revisions to the content, structure and presentation of the information were made in consultation with the steering group and an appropriate health professional to produce a final version of the information pack (11). Readability of the information pack was then assessed (12).

5.5 Professional evaluation

Each of the 10 draft topics in the information pack was independently evaluated by 1-3 health professionals (from a group of seven: a professor in medical science, a consultant gynaecologist, two genetic breast care nurses, a clinical psychologist and two health psychologists) who all had experience of working with women with a family history of breast/ovarian cancer and had not been involved in the preparation of those materials. These health professionals were given details of the aim, target sample and intended randomised controlled trial of the information pack. They rated the topics on four different dimensions (content, clarity, presentation and overall quality) on a 4-point scale from poor to very good (a copy of the evaluation form is in Appendix II, page 31). In addition they were asked to indicate if any relevant information was missing and if any irrelevant information was included. A summary of the ratings for all of the topics is shown in Table 5.2. The results show that at least 86% of the ratings for all of the topics on each aspect

were “good” or “very good”. Minor additions to some of the topics were suggested including information on dietary supplements and further details on HRT breast cancer treatment, the National Breast Screening Programme and participating in studies at the familial breast cancer clinic.

Table 5.2: Professional evaluation of the topics of information

Dimension:	Total ratings for the 10 topics (n = 21) ¹			
	Poor	Adequate	Good	Very Good
Content	0	2 (10%)	7 (33%)	12 (57%)
Clarity	0	3 (14%)	8 (38%)	10 (48%)
Presentation ^{2*}	0	2 (10%)	6 (29%)	12 (57%)
Overall Quality	0	2 (10%)	7 (33%)	12 (57%)

¹ 21 total ratings = 2 health professionals rated 2 topics (4 ratings), 3 health professionals rated 3 topics (9 ratings) and 2 health professionals rated 4 topics (8 ratings)

² The raters evaluated a draft document which was not in its final presentation format (i.e. without a file, topic dividers, title page and introduction to the pack)

* 4% = missing data

5.6 Pilot testing

The draft information pack was pilot tested on a small group of women living with an increased risk of breast cancer. The 25 women who participated in the telephone focus group study (Chapter 3) were invited by post to evaluate the draft information pack. Twelve women replied of whom eight were able to participate during the scheduled period of time. These women were sent the draft information pack and then telephoned at least one week later to evaluate the information pack.

Respondents were asked to rate the information pack as a whole on seven different dimensions (whether it covered the right amount of information/detail; was easy to understand/use; contained information new to the respondent; was upsetting; overall helpfulness) on a 10-point scale (a copy of the list of questions is in Appendix II, page 33). They were asked how much of the information pack they had read,

whether any relevant information was missing or irrelevant information included and whether they thought the printed leaflets were a useful addition.

Feedback on the draft information pack was extremely good (a summary of ratings is shown in Table 5.3).

Table 5.3: Results of pilot testing the information pack (N = 8)

Dimension	Scoring		Mode	Frequency of mode (n = 8)	Range
	0	10			
Amount of information	<i>too little</i>	<i>too much</i>	5	6	3-8
Amount of detail	<i>not enough</i>	<i>too much</i>	5	5	3-8
Easy to understand	<i>very easy</i>	<i>very difficult</i>	0	6	0-8
Information new	<i>none</i>	<i>all</i>	8	3	2-8
Information upsetting	<i>none</i>	<i>all</i>	0	8	0
Easy to use	<i>very easy</i>	<i>very difficult</i>	0	8	0
Overall helpfulness	<i>not at all</i>	<i>very</i>	10	6	8-10

Although seven out of the eight participants had read all 10 topics of information, they had not all read the three accompanying leaflets. There were mixed views about the inclusion of the three leaflets, some women thought they were not really necessary or helpful and others thought they were extremely useful. The main suggestions for improving the information pack were: simplification of the information given about breast cancer genetics and genetic testing including clearer diagrams, inclusion of information about the diagnosis of breast cancer and who to ask for advice about HRT.

All 12 women who offered to evaluate the information pack were sent a copy of the final information pack once the randomised controlled trial was completed.

5.7 Presentation

Several aspects of presentation were considered according to published guidelines (i.e. Ewles et al., 1985; Coulter et al., 1998; Centre for Health Information Quality, 1997,1999, 2000; Plain English Campaign, 2001a & b): word/sentence

length, text size/style, explanations of scientific/medical terms, layout of text, summary of main points, use of diagrams/icons, suggested further reading, ease of finding specific topics/other relevant pages.

The information pack was structured to provide the women with optional levels of detail: a low amount of detail was provided by the key points boxes summarising the main aspects of each topic; a moderate amount of detail was provided by the main text and if a high amount of detail was required, individuals could use the further reading sections provided at the end of each topic.

The presentation of the information pack was designed to be attractive and easy to use, whilst remaining inexpensive. The topics were separated by coloured cardboard dividers and placed in an A4-ring binder file with the accompanying leaflets included in a plastic pocket at the back of the file. A title page, introduction to the information pack, list of authors and contents pages were also included.

5.8 Readability

It is recommended that health information should be developed using a readability tool to ensure the information is suitable for the intended audience (Ewles et al., 1985; Centre for Health Information Quality, 1997; Coulter et al., 1998). Of the numerous readability tests available, two tests, which considered sentence length and word difficulty, were selected to assess the readability of the information pack. These tests were selected on the basis that they were quick, easy to use (could be manually undertaken) and had previously been used to assess publications written for the British population.

5.8.1 The Gobbledygook Test

The Gobbledygook test assesses the readability of written materials for adults and is based on the assumption that when polysyllabic words are put into long sentences comprehension generally becomes more difficult (Ewles et al., 1985). The test was modified by the Plain English Campaign from R. Gunning's Frequency of Gobbledygook (FOG) formula (Ewles et al., 1985). The test enables you to calculate an average sentence length and a percentage of long words in a sample of text (100 words) that when summed produces the test score (Ewles et al., 1985). As the test score increases, readability decreases. This is repeated using three different samples of text to produce a mean test score (Ewles et al., 1985). We used samples of text

from two scientific topics (breast cancer genetics and options for women with a family history of breast cancer) and one psychosocial topic (worry about breast cancer). The mean test score for the information pack was 37. Comparison scores of U.K. daily newspapers produced by the National Consumer Council in 1980 were "The Sun" (26) and "The Guardian" (39) (Ewles et al., 1985).

5.8.2 The SMOG Test (Simple Measure of Gobbledygook)

The SMOG test provides an estimate of the education level necessary for understanding written material (McLaughlin, 1969). The formula uses the total number of polysyllabic words in three samples of 10 consecutive sentences from a piece of written material (McLaughlin, 1969). We used samples from the same three topics that were used in the Gobbledygook test. The resulting American educational level or grade can be converted to a U.K. reading age by a simple calculation (Beaver et al., 1997). The reading score obtained for the information pack was 94 (i.e. expected reading ability of an 18 year old in the U.K.). Published comparison scores include an article in the "British Medical Journal" on healthy eating (122) and an article in the Radio Times magazine (49) (Beaver et al., 1997).

5.8.3 Limitations of readability tests

The results of the readability tests suggest that a fairly high level of reading ability would be required to read the information pack. However, in terms of reading ability, our intended recipients are unlikely to be representative of the general population. They are likely to be highly educated (e.g. just over half of participants in our previous cross-sectional study had received further education/training after age 18) as is commonly found in recipients of health screening (Rimer et al., 1996).

Although readability tools are a useful estimate of whether health information is suitable for a specific group of people, these tests do not consider numerous other factors, which may influence the complex process of reading (Smith et al., 1998). These include the presentation of the information (including diagrams), the situation in which the information is read (which may be stressful), certain characteristics of the reader and their familiarity with relevant vocabulary (e.g. recipients of the information pack are likely to be familiar with some of the terms associated with familial breast cancer) (Smith et al., 1998).

5.9 Final contents of the information pack

The final version of the information pack contained 10 topics of information (total of 45 A4-pages of text and diagrams) and three published leaflets to accompany topics 3, 4 and 9 (see Table 5.4 for a summary of contents and Appendix III for a copy of the information pack).

Two versions of the information pack were produced for use in the subsequent randomised controlled trial: The scientific and psychosocial information pack (which contained all 10 topics and three leaflets) and the scientific information pack (which contained all topics and leaflets except the two psychosocial topics and accompanying “How to...stop worrying “ leaflet).

5.10 Discussion

The development of the information pack for women living with an increased risk of breast cancer was an iterative process involving a multi-disciplinary steering group, professional evaluation, pilot testing and assessment of readability. The format and content of the information pack were based on data collected in previous studies (see Chapters 3 and 4) and were supported by research findings on written interventions in other populations.

The information pack that was produced contained up-to-date and reliable information covering both scientific and psychosocial topics related to familial risk of breast cancer. It aimed to improve knowledge and reduce cancer worry. Evaluation of the information pack by a number of health professionals confirmed that the quality was good. Feedback from several women attending the familial breast cancer clinic suggested that the information pack was extremely relevant for this group of women.

The effectiveness of the information pack was then evaluated in a randomised controlled trial.

Table 5.4: Summary of the contents of the information pack

Topic	Title of topic/leaflet	Description
1	Introduction to breast cancer	Explains the development of cancer, its causes and gives a general background to breast cancer
2	Breast cancer genetics	Describes genes, genetic mutations and their role in the inheritance of susceptibility to breast cancer
3	Genetic testing	Explains the process of and criteria for genetic testing for BRCA1/2
	Cancer genetics	Leaflet produced by the South East of Scotland Clinical Genetics Service which outlines criteria for familial cancer screening programmes and advice about genetic testing
4	Options for women with a family history of breast cancer	Covers screening (mammography, clinical breast examination, breast awareness) and risk reduction (prophylactic surgery, Tamoxifen)
	Breast awareness	Leaflet produced by Breast Cancer Care which gives practical advice on being breast aware
5	Hormone replacement therapy (HRT)	Includes a summary of research on HRT and the risk of breast cancer
6	Diagnosis and treatment of breast cancer	Includes a summary of the diagnostic procedure and local/systemic treatments for breast cancer
7	Research at the Ardmillan familial breast cancer clinic	A summary of recent scientific and psychosocial research conducted at the familial breast cancer clinic
8*	Healthy lifestyle	Includes a summary of research on lifestyle and breast cancer risk and guidelines on several aspects of maintaining a healthy lifestyle
9*	Worry about breast cancer	Includes advice on how to critically appraise media reports about breast cancer and self-help strategies for relieving worry
	How to... stop worrying	Leaflet produced by MIND which suggests a variety of ways to help reduce worry.
10	Sources of Information	Lists useful local, national and international organisations and their contact details (including web page address) and the references that were used to write the pack

* Indicates psychosocial topic of information

Chapter 6: Randomised Controlled Trial of a Psychoeducational Intervention in Women Living with an Increased risk of Breast Cancer

6.1 Introduction

A number of interventions have been evaluated in women with a family history of breast cancer (e.g. Gagnon et al., 1996; Lerman et al., 1996; Cull et al., 1998; Schwartz et al., 1998; Watson et al., 1998; Audrain et al., 1999; Kash et al., 1999; Wellisch et al., 1999; Esplen et al., 2000). These have varied greatly in terms of their aims (e.g. reducing psychological distress, improving adherence to breast self-examination), sample (e.g. first-degree relatives of recently diagnosed breast cancer patients, high-risk women maintained on regular clinical surveillance) and format of the intervention (e.g. newsletter, Problem-Solving Training). The studies of particular interest to the current trial have investigated the impact of psychoeducational group interventions in American women at high-risk of developing breast cancer (i.e. Kash et al., 1999, Wellisch et al., 1999).

Wellisch et al. (1999) carried out a pilot study of a short-term group intervention that provided education, psychological support and skills training in order to treat psychological distress. Thirty-three women, enrolled in a high-risk breast cancer surveillance program, received the intervention which consisted of a weekly group meeting lasting for 2.5 hours for six consecutive weeks. Each group meeting included educational (e.g. genetics, nutrition, relaxation, medical information) and psychological components (e.g. share experiences, family relationships, coping, anger management), which were led by an appropriate health professional. Several variables were assessed pre- and post-intervention (immediately after the last group session) of which only generalised anxiety and depression have so far been reported. Statistically significant reductions both in depression and state anxiety were observed. However, as the authors acknowledge, there are a number of methodological limitations of the study: the lack of control group/long-term follow-up and small sample size.

Kash et al. (1999) have reported the preliminary results of a randomised controlled trial of a similar psychoeducational group intervention. The intervention is being evaluated in relation to knowledge of breast cancer, beliefs about breast cancer, breast cancer-specific anxiety, quality of life, adherence to breast cancer screening and coping skills. At the time of reporting, 192 women at high-risk for

breast cancer had been randomised to the intervention or control condition. The intervention consisted of educational, social support enhancement, problem-solving and cognitive restructuring components in 1.5-hour group sessions every week for six weeks with additional sessions at six months and one year. Women in the intervention group experienced a statistically significant decrease in breast cancer-specific anxiety and perceived risk and improvement in knowledge between their first assessment prior to randomisation and their fourth assessment one year later.

Despite the fact that the full details of these two American studies have yet to be published, the preliminary results are nevertheless encouraging. There is now a need to investigate whether long-term attendees of a British familial breast cancer clinic would benefit from similar psychoeducational intervention.

6.2 Rationale

For long-term attendees of the Ardmillan familial breast cancer clinic in South East Scotland, contact with the clinic is limited to follow-up breast cancer screening appointments. These appointments are generally scheduled at yearly intervals, but their frequency and duration has become increasingly limited as clinical services are stretched by a growth in referrals and the number of women under surveillance accrues. This leads to the impetus for more stringent criteria for surveillance. Clinical services other than breast cancer screening such as psychosocial support or education are not routinely provided for this group of women.

The cross-sectional study (Chapter 4) confirmed the results of the telephone focus group study (Chapter 3) in terms of a widespread need for up-to-date, reliable information related to familial risk of breast cancer in women living with an increased risk of the disease. There was an overall preference for the information to be presented in a written format. The cross-sectional study also showed a high prevalence of worries about breast cancer risk-related issues.

Given the need for information and the prevalence of worry in women living with an increased risk of breast cancer, a psychoeducational written intervention was developed (Chapter 5). It intended to provide these women with access to up-to-date information on scientific and psychosocial topics related to familial risk of breast cancer in order to improve their knowledge and reduce cancer worry.

6.3 Aims

Main aim:

- To determine the impact of a psychoeducational written intervention on cancer worry (primary outcome) and objective knowledge of breast cancer risk-related topics (secondary outcome).

Subsidiary aims:

- To explore the impact of a psychoeducational written intervention on breast cancer specific-distress (as measured by the Impact of Event Scale), generalised psychological distress (as measured by the GHQ-12) and appraisal (as measured by perceived risk, perceived likelihood and perceived control over developing breast cancer).
- To evaluate the acceptability of the psychoeducational written intervention for women living with an increased risk of breast cancer.

6.4 Hypotheses

The hypotheses relate to the main aim of the study.

- The addition of Scientific + Psychosocial Written Information to standard care (Group 1) will reduce cancer worry to a greater extent than the addition of Scientific Written Information alone (Group 2) (standard care refers to the regular clinical surveillance provided by the familial breast cancer clinic in accordance with clinical guidelines based on age and family history: see Section 1.4.2, page 12).
- Scientific Written Information in addition to standard care (Group 2) will reduce cancer worry to a greater extent than standard care alone (Group 3).
- Written Information in addition to standard care (Groups 1 and 2) will improve objective knowledge of breast cancer risk-related topics to a greater extent than standard care alone (Group 3).

6.5 Design

A randomised controlled trial comparing three groups of participants:

- Group 1: Scientific + Psychosocial information pack in addition to standard care.
- Group 2: Scientific information pack in addition to standard care.
- Group 3: Standard care (control group).

All three groups were assessed at baseline (prior to receiving the information pack) and post-intervention (approximately four weeks later) by postal questionnaire.

6.6 Participant selection

Women who participated in the cross-sectional study (n = 249) (see Section 4.5, page 86 for eligibility criteria and Section 4.9, page 95 for recruitment to the cross-sectional study) who met the additional criteria in Table 6.1 were invited to participate.

Table 6.1: Entry criteria for the randomised controlled trial

Inclusion criteria:

- Indicated in the cross-sectional questionnaire study that they were interested in at least one of the intervention options listed.

Exclusion criteria:

Since participating in the cross-sectional questionnaire study:

- Been discharged from the clinic.
- Joined the International Breast Cancer Intervention Study (IBIS) or Magnetic Resonance Imaging (MRI) Trial.
- Undergone genetic testing.

6.7 Sample size calculation

A recent study of 116 women who attended the Ardmillan Familial Breast Cancer Clinic in South East Scotland, found that Cancer Worry Scale (CWS) scores

were fairly normally distributed and ranged from 6-19, mean = 10.65, standard deviation = 2.58 (Rees, 2000, Personal communication). When estimating sample sizes, an “effect size” of 0.5 is generally regarded as moderately large (Fayers & Machin, 2000).

Given that there is a lack of data to suggest what constitutes a clinically significant change on the CWS, the calculations for the present study were based on an effect size of 0.5 ($0.5 \times 2.58 = 1.3$) where the mean change in scores has been rounded up to 1.5 (to allow for greater variability in CWS scores in this sample).

To detect a difference of 1.5 on the CWS with an 80% power at a significance level of 5%, a minimum sample size of 138 (i.e. 46 women in each of the three intervention groups) was required.

6.8 Randomisation

Participants were randomised to one of the three intervention groups at the point of recruitment (i.e. when they had returned a consent form agreeing to participate). Restricted randomisation using the random permuted blocks method (Pocock, 1983) was undertaken to ensure that there were equal numbers of participants in each of the three intervention groups. For each block of three participants, there was a different random order of the three intervention groups. The numbers 1-6 were assigned to the six different possible orders of the three intervention groups (If S = scientific group, P = psychosocial + scientific group and C = control group, then: 1 = SPC, 2 = SCP, 3 = CSP, 4 = CPS, 5 = PCS and 6 = PSC). A table of random numbers from 1-6 was generated in Microsoft Excel and participants were assigned to the corresponding order of the intervention groups.

6.9 Intervention

The intervention was a psychoeducational written information pack consisting of scientific and psychosocial topics of information and three accompanying published leaflets (see Chapter 5 on the development of the information pack).

6.10 Measures

6.10.1 Baseline only

Sociodemographic and risk variables:

Data were already available from the cross-sectional study (data collected August 2000 - January 2001) to describe the sociodemographic characteristics of the women participating in this study in terms of their: education, marital status, occupation and number of children.

Several additional characteristics of the women were assessed at baseline: age, number of years of attendance at the familial breast cancer clinic and objective breast/ovarian cancer risk. A standard estimate of both breast and ovarian cancer risk were devised by a specialist registrar in clinical genetics (advised by a consultant in clinical genetics). The risk estimates originally given to the women during genetic risk counselling were extracted from the case notes. These were updated using current clinical guidelines for deriving individual risk estimates from family history (i.e. Scottish Executive, 2001) and additional epidemiological information to give the standard estimates reported in this study. Objective breast cancer risk was classified as: low (<17% lifetime risk), medium low (17-19%), medium (20-22%), medium high (23-25%), high (>25%). Objective ovarian cancer risk was classified as: low (<3% lifetime risk), medium (3-5%), high (>5%).

Coping style:

Data from assessments of the following coping styles were also extracted from the cross-sectional study: monitoring, blunting, emotional uncertainty and cognitive uncertainty.

6.10.2 Baseline and Post-intervention

6.10.2a Key outcomes

Cancer Worry Scale (CWS):

This 6-item scale assesses concerns about developing cancer and the impact of cancer worry on daily functioning in terms of its frequency and severity (a copy of the scale is included in Appendix II page 36). It was based on a number of items that were originally used to assess worry about cancer in American women with a family history of breast cancer (Lerman et al., 1991a, 1991b, 1993, 1994). More recently it

has been modified to form a 6-item scale applicable to British women (Watson et al., 1998). Responses are organised on a 4-point Likert scale (e.g. "How much of a problem is worrying about cancer to you?" 1 = not at all, 4 = severe problem) and are summed to produce a total score of 6-24. The higher the total score, the greater the cancer worry. Clinical threshold scores for this scale have not yet been derived.

The psychometric data available on the scale are satisfactory: internal consistency (Brain et al., 1999: Alpha = .86; Hopwood et al., 2001: Alpha = .86; Rees, 2000, Personal communication: Alpha = .80), test-retest reliability (Rees, 2000, Personal communication: .742), concurrent validation with the GHQ-30 total score (Rees, 2000, Personal communication: .347, $p < 0.01$) and the Impact of Event Scale total score (Rees, 2000, Personal communication: .572, $p < 0.01$). A principal components factor analysis has also been undertaken on the scale confirming its appropriateness as a unitary scale (one factor was extracted explaining 59.5% of the variance) (Hopwood et al., 2001).

It has been used to assess breast cancer worry in British women with a family history of breast cancer both before (Brain et al., 1999; Hopwood et al., 2001; Watson et al., 1998) and after genetic risk counselling (Hopwood et al., 2001; Rees, 2000, Personal communication; Watson et al., 1998). It has also previously been used in women attending the same familial breast cancer clinic as the women in the present study (Rees, 2000, Personal communication).

Objective knowledge of breast cancer risk-related topics:

Thirty-six items were devised specifically for this study to assess objective knowledge of breast cancer risk-related topics (a copy of these items is included in Appendix II page 36). These items were devised by the multidisciplinary group who developed the information pack and were based on the key points covered in the scientific topics of information about breast cancer genetics, genetic testing, breast cancer screening and HRT. The items were designed to assess understanding of key points of information (as determined by appropriate health professionals) rather than simply recall of information (e.g. "The main cause of all breast cancer is: inherited genetic susceptibility?"). The responses were formatted as true, false or don't know. The number of correct, incorrect and don't know responses were summed separately to produce three total scores all ranging from 0-36.

6.10.2b Exploratory variables (i.e. variables that may be affected by the intervention)

Breast cancer-specific distress:

The Impact of Event Scale (Horowitz et al., 1979) is a 15-item scale which determines levels of breast cancer-specific distress in terms of intrusive and avoidant thoughts about breast cancer in the past week (Kash et al., 1992) (see Section 4.6.5a, page 89 for a full description of the scale).

General psychological distress:

The 12-item version of the General Health Questionnaire (GHQ-12) is a first-stage screening test to detect current psychiatric disorders in community and non-psychiatric clinical locations (Goldberg & Williams, 1991). Responses are in four categories, were scored 0,0,1,1 and a threshold score of three was used to detect "case-level" distress (see Section 4.6.4a, page 88 for a full description of the scale).

Appraisal:

Three single items were used to assess perceived risk of developing breast cancer in relation to the general population, perceived likelihood of developing breast cancer and perceived control over developing breast cancer (see Section 4.6.7, page 90 for a full description of the items).

6.10.2c Additional variables

Waiting for results:

One study-specific item asked participants if they were currently waiting for the results of a mammogram or breast biopsy. The responses were on a simple yes/no format.

6.10.3 Post-intervention only

Evaluation of the intervention (Groups 1 and 2 only):

A number of items were used to obtain feedback from the women on the information pack in terms of (a copy of the items is included in Appendix II page 45):

- the number of times they read the topics/leaflets
- when they last read any of the information pack
- to what extent the information included in each topic was new to them

- if they discussed or gave the information pack to anyone else
- if they found any topics/leaflets difficult to understand, upsetting or helpful
- if they had changed or intend to change any of their health behaviours as a result of reading the information pack
- if they intended to obtain any of the further reading listed
- if they thought any topics were missing from the pack
- if the information pack covers their need for information and support

Other breast cancer information (Group 3 only i.e. standard care):

Participants were asked if they had read any information related to familial risk of breast cancer in the past month.

6.11 Procedure

The Regional Ethics Committee approved the study. Figure 6.1 shows the study procedure.

Potential participants were sent a letter inviting them to take part together with an information sheet explaining the randomisation procedure, a consent form and Freepost envelope. They were asked to return the consent form in the Freepost envelope indicating whether or not they were willing to participate. With the participant's permission, their GP received a letter informing them that their patient had agreed to participate together with a copy of the information sheet. If a completed consent form was not received within three weeks, the participant was sent a reminder.

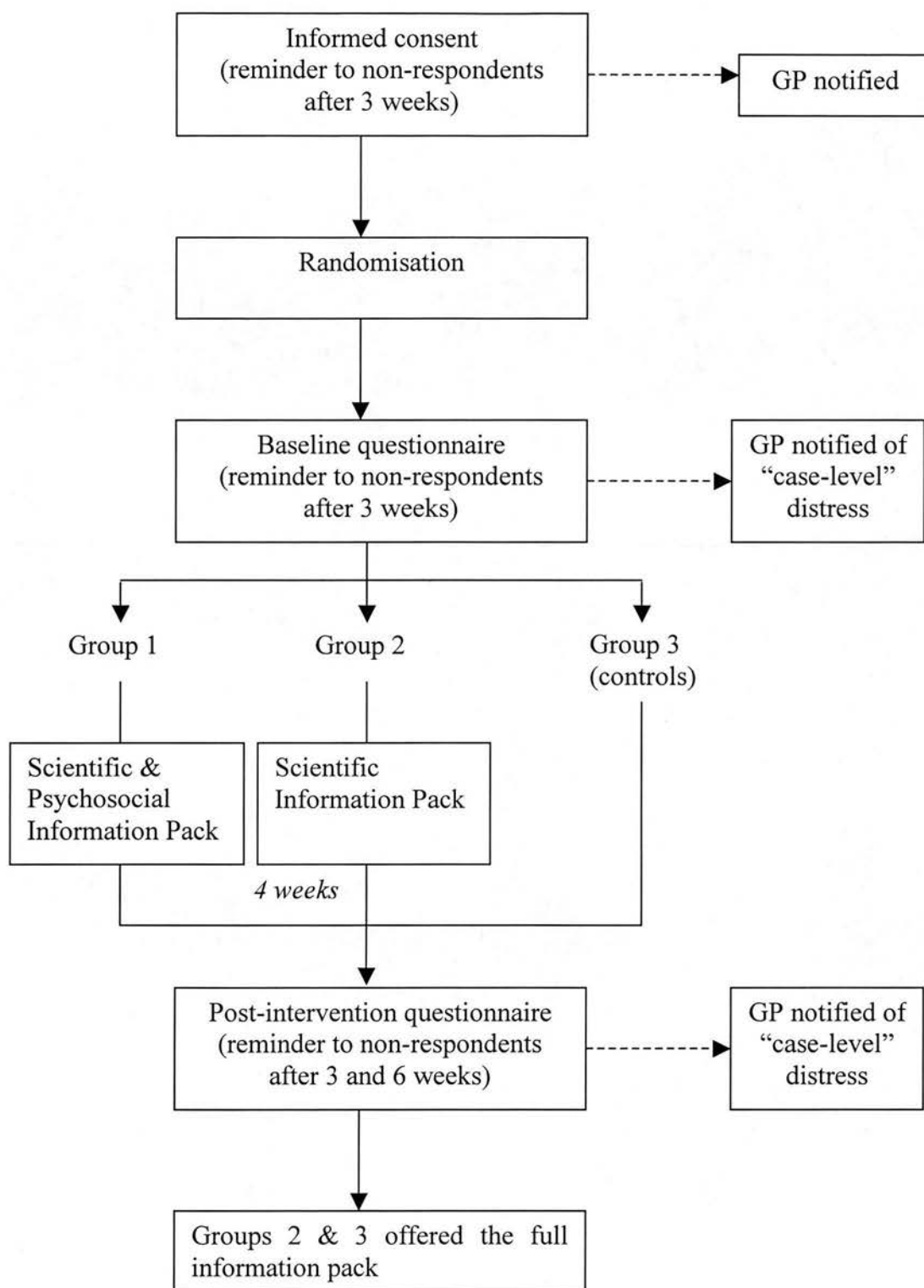


Figure 6.1: Summary of the procedure for the randomised controlled trial

Participants who consented to the study were sent the baseline questionnaire and letter notifying them to which of the three groups they had been randomised. On return of the completed baseline questionnaire (a copy is in Appendix II, page 36), participants in Groups 1 (scientific and psychosocial information) and 2 (scientific information) were sent the appropriate information pack and covering letter. If a completed baseline questionnaire was not received within three weeks, the participant was sent a reminder. The post-intervention questionnaire (a copy of the questionnaire for Group 1 is in Appendix II, page 45) and covering letter were sent to participants four weeks after sending them an information pack (Groups 1 and 2) or four weeks after they returned a completed baseline questionnaire (Group 3 – control group). If a completed post-intervention questionnaire was not received within three weeks, participants were sent a reminder. If a completed post-intervention questionnaire still had not been received within six weeks, participants were sent a second reminder. At the end of the post-intervention questionnaire Groups 2 and 3 were offered the full written information pack (i.e. Group 2: Psychosocial topics, Group 3: Scientific and Psychosocial topics). Any participant in these groups who requested the full information pack was sent it immediately together with a letter thanking them for participating in the study.

The GP was promptly notified by letter if their patient was found to score above the clinical case threshold (i.e. ≥ 3) on the GHQ-12 at either baseline or post-intervention (on recruitment to the study, participants had given their consent for their GP to be passed any information collected during the study).

Any participants in Groups 1 or 2 who indicated that they found some of the topics in the information pack upsetting were immediately contacted by post to ask if it would be possible to discuss their upset on the telephone.

6.12 Statistical analysis

The distribution of all continuous variables was assessed for each randomised group to determine their parametric or non-parametric nature. The appropriate descriptive statistics were generated to describe the study participants. Differences between two independent groups were analysed with independent samples t-tests (2-tailed) or Mann-Whitney tests.

Cancer worry: Comparisons of the three randomised groups on CWS total score at baseline and post-intervention were made using the Kruskal-Wallis test. Changes in

CWS total score between baseline and post-intervention were assessed for each of the three groups (only for women with data at both assessments) by the Wilcoxon matched-pairs signed-rank test. Individual changes in CWS total score from baseline to post-intervention were calculated and median changes, ranges and proportions of changes (increased/stayed the same/decreased) were compared for the three groups.

Objective knowledge of breast cancer risk-related topics: Comparisons of the three randomised groups on objective knowledge: total correct, total incorrect and total don't know at baseline and post-intervention were made using the Kruskal-Wallis test. Changes in the objective knowledge totals between baseline and post-intervention were assessed for each of the three groups (only for women with data at both assessments) by the Wilcoxon matched-pairs signed-rank test. Individual changes in objective knowledge total scores from baseline to post-intervention were calculated and median changes, ranges and proportions of changes (increased/stayed the same/decreased) were compared for the three groups.

Sociodemographic and Exploratory variables: Comparisons of the three randomised groups on the demographic and exploratory variables at baseline and post-intervention were made using the chi square test (2-tailed), one-way ANOVA or Kruskal-Wallis test. Changes in the exploratory variables between baseline and post-intervention were assessed for each of the three groups (only for women with data at both assessments) by the McNemar test or Wilcoxon matched-pairs signed-rank test. Spearman's rank correlation (2-tailed) was used where appropriate.

Evaluation of the information pack: The appropriate descriptive statistics were generated to summarise feedback on the information pack. Comparisons of Group 1 and Group 2 were made using chi square tests (2-tailed).

A number of categorical variables were recoded for the purposes of between-group/within-group analysis: breast cancer risk estimate (low or medium low/medium/medium high or high), perceived likelihood of developing breast cancer (unlikely/likely), perceived control over developing breast cancer (no control/some control), marital status (married or living with a partner/not married or living with a partner) and occupation (employed/not employed).

The absence of one or more scores on a scale resulted in that total score being classified as missing. As there is missing data across the various measures for the sample at both assessment points, the numbers analysed for each variable will be

specified throughout. Data were analysed on an intention-to-treat basis. A significance level of 0.05 was used throughout. The data were analysed using SPSS for Windows version 10.00 (1999).

6.13 Results

6.13.1 Baseline

6.13.1a *Participants*

Figure 6.2 summarises participant recruitment to the study. Of the 249 women who participated in the cross-sectional questionnaire study, 41 did not meet the additional criteria to participate in the intervention study (17 had been discharged from the clinic since participating in the cross-sectional study for various reasons such as they had been referred to the National Breast Screening Programme or they were deemed to be at low risk, two were recent recruits to the MRI trial and 22 indicated in the cross-sectional study that they were not interested in any of the intervention options listed).

Of the 208 women who were invited to participate in the randomised controlled trial, 11 refused (only one woman gave a reason: moving house), two women responded too late to be randomised (three months after the initial invitation) and 23 women did not reply to the invitation. Of the 172 women who consented to participate, were randomised and sent the baseline questionnaire, 8 (from Group 1 = 1; Group 2 = 4; Group 3 = 3) did not return the questionnaire and one woman (randomised to Group 3) was excluded from the analysis because of a protocol violation (she had been discharged from the clinic prior to randomisation and therefore should not have been invited to participate). Therefore, 163 baseline questionnaires were included in the analysis (Group 1 = 56, Group 2 = 53, Group 3 = 54).

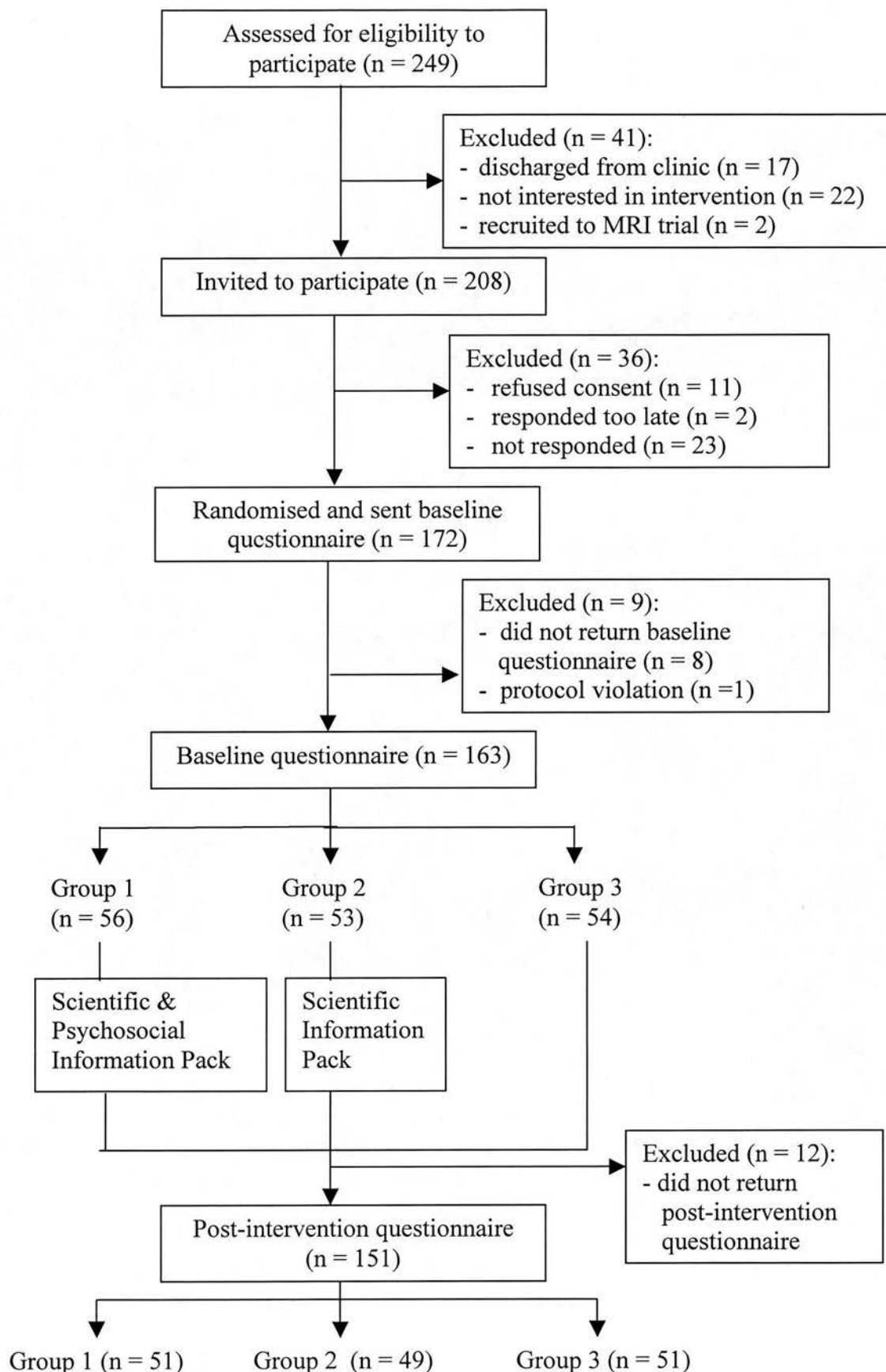


Figure 6.2: Progress of participants through the randomised controlled trial

There were no significant differences between the participants at baseline (n = 163) and non-participants (n = 45 including the eight women who didn't return the baseline questionnaire and the woman who was excluded from data analysis) on any of the sociodemographic or psychological trait variables extracted from the cross-sectional questionnaire study or characteristics assessed at baseline (age, number of years clinic attendance and objective breast cancer risk). Although differences between participants and non-participants on objective ovarian cancer risk could not be tested as the number of women in each category was too small, the data were nevertheless comparable (low: n = 137, 91%/n = 35, 92%; medium: n = 12, 8%/n = 3, 8%; high: n = 1, 1%/n = 0).

6.13.1b Sociodemographic and risk variables

The mean age of participants was 43.9 years (SD = 6.57) and ranged from 28-62 years. They had been attending the Ardmillan Familial Breast Cancer Clinic for 2.75- 8.51 years (mean = 5.26, SD = 1.72). The majority of participants were married or living with a partner (n = 137, 86%) with the remainder being single (n = 11, 7%) or divorced/separated (n = 11, 7%). The median number of children was 2 (range 0-4). As far as education was concerned, 53 women (33%) had received schooling until age 16 only whereas 27 (17%) had attended school/further education/training until age 18, 38 (24%) had further education or training after age 18 and 44 (27%) were university graduates. Most participants were employed either full-time (n = 73, 45%) or part-time (n = 62, 38%) with 18 women (11%) having home duties, six were unemployed (4%) and four were retired (3%).

The majority were estimated to be at medium risk of breast cancer (n = 80, 53%) with 41 (27%) assigned a medium high risk, 15 (10%) medium low, nine (6%) low and five (3%) high. Most participants had a low risk of ovarian cancer (n = 137, 91%) with 12 (8%) at medium risk and one woman (1%) at high risk. As the clinical case notes for 13 participants were unable to be located, their objective breast and ovarian cancer risks were not calculated.

There were no significant differences between the three groups on any of the sociodemographic or risk variables apart from objective ovarian cancer risk where the numbers in each category were too small to be tested.

6.13.1c Coping Style

The mean score for the whole sample on the Monitoring subscale was 3.9 (SD = 1.57) and on the Blunting subscale was 1.94 (SD = 1.32). The median score on the Emotional Uncertainty subscale was 30 (range = 20-56). There were no significant differences between the three groups at baseline on any of these coping style variables. However, the three groups were significantly different in their scores on the Cognitive Uncertainty subscale ($F(2, 156) = 3.103, p = .048$) (Table 6.2). A correlation that was approaching significance was observed between scores on the Cognitive Uncertainty subscale and baseline scores on the Cancer Worry Scale (Spearman's $\rho = 0.152, p = .056$).

Table 6.2: Comparison of the three groups in scores on the Cognitive Uncertainty subscale at baseline

Cognitive Uncertainty	Total Sample	Group 1	Group 2	Group 3
N	159	52	53	54
Mean	46.39	45.35	45.34	48.43
SD	7.49	7.72	6.61	7.78

6.13.1d Psychological distress

The median Cancer Worry Scale (CWS) score for the total sample at baseline was 9 (range = 6-21).

Seventy-one women (44%) indicated at baseline that they had thought about the risk of breast cancer in the past week. The median score on the intrusion subscale of the IES for the total sample at baseline was 6 (range = 0-33), the median score on the avoidance subscale of the IES was 9 (0-30) and median total IES score was 14 (range = 0-59).

The median GHQ-12 total score at baseline was 0 (range 0-12). Forty-seven women (29%) were suffering from “case-level” distress (score of ≥ 3).

Table 6.3 compares scores on the psychological distress measures for each of the three groups at baseline. There were no significant differences between the three groups on any of the psychological distress measures at baseline. The small sample sizes for the IES scores are due to fact that the majority of participants did not complete the IES as they had not thought about the risk of breast cancer in the past week (i.e. there was only a small amount of missing data).

Table 6.3: Comparison of the three groups at baseline

Variable		Group 1	Group 2	Group 3
Cancer Worry Scale	N	56	53	53
	Median	9	9	10
	Range	6-20	6-17	6-21
Objective knowledge:	N	48	46	46
	Median	17.5	17	15
	Range	6-28	8-35	7-31
Total correct	Median	9	8	8
	Range	3-18	1-19	1-15
Total incorrect	Median	9	10.5	12
	Range	0-23	0-21	0-22
IES:				
	N	21	21	29
	Median	8	6	5
Intrusion	Range	0-33	0-25	0-27
	N	19	20	28
	Median	9	8	9
Avoidance	Range	0-26	0-23	0-30
	N	19	20	28
	Median	18	12.5	13
Total	Range	0-59	0-47	0-51
	N	56	51	54
	Median	1	0	0
GHQ-12:	Range	0-11	0-12	0-12
	Case	17 (30%)	10 (20%)	20 (37%)
	Non-Case	39 (70%)	41 (80%)	34 (63%)
“Case-level” distress				
	N	56	53	54
	Lower than	1 (2%)	0	0
Appraisal:	The same as	4 (7%)	5 (9%)	0
	Slightly higher than	37 (66%)	35 (66%)	40 (74%)
	Much higher than	14 (25%)	13 (25%)	14 (26%)
Perceived risk of developing breast cancer (in relation to the general population)	N	56	51	52
	Unlikely	15 (27%)	13 (26%)	17 (33%)
	Likely	41 (73%)	38 (75%)	35 (67%)
Perceived likelihood of developing breast cancer	N	56	53	54
	None at all	18 (32%)	21 (40%)	16 (30%)
	Some	38 (68%)	32 (60%)	38 (70%)
Perceived control over developing breast cancer				
	N	56	53	54
	None at all	18 (32%)	21 (40%)	16 (30%)
	Some	38 (68%)	32 (60%)	38 (70%)

6.13.1e Objective knowledge

Objective knowledge of breast cancer risk-related topics at baseline was generally poor (the distribution of responses to the individual objective knowledge items is in Appendix II, page 60). The mean number of correct responses for the whole sample was 16.4 (SD = 6), which represents 44% of the total questions. The mean number of incorrect responses was 8.5 (SD = 3.5), corresponding to 24% of the total questions. The mean number of responses the participants didn't know was 11.1 (SD = 5.5), representing 31% of the total questions.

Table 6.3 compares the objective knowledge total scores for each of the three groups at baseline. There were no significant differences between the three groups at baseline on any of the objective knowledge total scores.

6.13.1f Appraisal

The majority of participants at baseline thought that their risk of ever developing breast cancer was slightly higher (n = 112, 69%) or much higher (n = 41, 25%) than the general population. Nine women (6%) perceived their risk to be the same as the general population and one woman (1%) thought that her risk was lower than the general population.

At baseline, most participants felt that it was at least likely that they would ever develop breast cancer (likely: n = 91, 57%; very likely: n = 21, 13%; inevitable: n = 2, 1%). Forty-four women (28%) felt that they were unlikely to ever develop breast cancer and only one woman (1%) felt she was very unlikely.

Most participants at baseline felt they had some control over whether they ever developed breast cancer (a bit: n = 71, 44%; moderate: n = 33, 20%; a lot: n = 4, 3%) compared to 55 (34%) who felt that they didn't have any control.

Table 6.3 compares the scores on appraisal measures for each of the three groups at baseline. There were no significant differences between the three groups at baseline on perceived likelihood of developing breast cancer or perceived control over developing breast cancer. Due to the small numbers of participants in some categories, between-group differences in perceived risk (relative to the general population) could not be tested (the categories could not meaningfully or effectively be combined).

6.13.1g *Waiting for results*

Nine women (6%) at baseline (three women in each group) stated they were currently waiting for the results of a mammogram or breast biopsy (between-group differences were not tested due to small numbers in one category).

6.13.2 Post-intervention

6.13.2a *Participants*

Figure 6.2 summarises the participants' progress through the study. Twelve women (from Group 1 = 5; Group 2 = 4; Group 3 = 3) dropped out of the study between baseline and post-intervention (i.e. they did not return the post-intervention questionnaire).

The number of women completing both questionnaires was 151 (Group 1 = 51, Group 2 = 49, Group 3 = 51), therefore exceeding the minimum sample size requirement of 138. The participation rate for the completing both questionnaires was 73% (151/208). The number of weeks between completing the baseline (data collected April-June 2001) and post-intervention (data collected June-September 2001) questionnaires ranged from 4.71-17.57 (mean = 7.51, SD = 2.5). The majority of participants in Groups 2 and 3 post-intervention requested to be sent the full information pack (Group 2: $n = 35$, 71%, Group 3: $n = 48$, 94%).

Differences between participants who only completed the baseline questionnaire (baseline only group, $n = 12$) and those who completed both questionnaires (study sample, $n = 151$) could not be tested due to the small sample size. Scores on the psychological distress and objective knowledge measures in these two groups were comparable at baseline (Table 6.4). However, the Impact of Event Scale median scores for the baseline only group were more than twice those of the study sample (Table 6.4).

Table 6.4: Comparison of participants who only completed the baseline questionnaire (Group A) and those who completed both questionnaires (Group B) on psychological distress and objective knowledge

Variable		Group A	Group B
Cancer worry	N	12	150
	Median	8.50	9.50
	Range	6-21	6-20
Objective knowledge:	N	10	130
	Total correct		
	Median	16	16
	Range	6-28	6-35
	Total incorrect		
	Median	9.5	8
	Range	1-14	1-19
Total don't know	Median	11	11
	Range	5-18	0-23
IES:			
	Intrusion		
	N	4	67
	Median	13.5	5
	Range	11-18	0-33
	Avoidance		
	N	4	63
	Median	19	9
	Range	9-23	0-30
	Total		
GHQ-12:	N	11	150
	Median	0	0
	Range	0-11	0-12
	“Case-level” distress		
	Frequency	3	44
	Percentage	27%	29%

6.13.2b Comparison of the three groups post-intervention

Table 6.5 summarises scores for each of the three groups on the psychological distress, objective knowledge and appraisal variables post-intervention.

Fifty-two women (35%) post-intervention indicated that they had thought about the risk of breast cancer in the past week and therefore completed the IES.

Eight women (5%) post-intervention stated they were currently waiting for the results of a mammogram or breast biopsy (four in Group 1 and four in Group 3). Only one of these eight women (from Group 3) had indicated at baseline that she was waiting for her results.

There were no significant differences on any of these variables between the three groups post-intervention apart from on objective knowledge and perceived control (perceived risk and waiting for results were not tested due to small numbers in some categories). There were significant differences between the three groups on objective knowledge: total correct ($\chi^2 = 37.387$, $df = 2$, $p = .000$), objective knowledge: total incorrect ($\chi^2 = 6.760$, $df = 2$, $p = .034$), objective knowledge: total don't know ($\chi^2 = 37.487$, $df = 2$, $p = .000$) and perceived control ($\chi^2 = 7.711$, $df = 2$, $p = .021$).

Of the women in Group 3 who were asked if they had read any information related to familial risk of breast cancer in the past month, only two (4%) had read any such information which covered breast awareness ($n = 1$) and genetic testing ($n = 1$).

Table 6.5: Comparison of the three groups post-intervention

Variable		Group 1	Group 2	Group 3
Cancer worry	N	50	49	50
	Median	9	9	9
	Range	6-16	6-24	6-16
Objective knowledge: Total correct	N	39	39	44
	Median	24	27	15
	Range	3-33	11-36	5-33
Total incorrect	Median	8	7	9
	Range	2-18	0-13	2-17
Total “don’t know”	Median	2	1	12.50
	Range	0-26	0-16	0-25
IES:				
Intrusion	N	13	17	20
	Median	9	11	3.5
	Range	0-13	0-35	0-25
Avoidance	N	14	15	20
	Median	10.5	16	5.5
	Range	0-29	0-40	0-30
Total	N	13	15	20
	Median	18	30	8.5
	Range	0-42	0-75	0-51
GHQ-12: Total	N	51	49	49
	Median	0	0	0
	Range	0-11	0-12	0-10
	Case	7 (14%)	7 (14%)	12 (25%)
	Non-Case	44 (86%)	42 (86%)	37 (76%)
Appraisal:				
Perceived risk of developing breast cancer (in relation to the general population)	N	50	48	51
	<i>Lower than</i>	0	0	0
	<i>The same as</i>	6 (12%)	3 (6%)	2 (4%)
	<i>Slightly higher than</i>	37 (74%)	35 (73%)	36 (71%)
	<i>Much higher than</i>	50	48	51
Perceived likelihood of developing breast cancer	N	47	46	50
	<i>Unlikely</i>	16 (34%)	19 (41%)	14 (28%)
	<i>Likely</i>	31 (66%)	27 (59%)	36 (72%)
Perceived control over developing breast cancer	N	50	48	51
	<i>None at all</i>	6 (12%)	14 (29%)	18 (35%)
	<i>Some</i>	44 (88%)	34 (71%)	33 (65%)

6.13.2c Participant feedback on the information packs

Feedback on the two different versions of the information pack was obtained as part of the post-intervention assessment of women in Group 1 (n = 51) and Group 2 (n = 49) only.

In Group 1, who were sent 13 topics of information and leaflets, the mean number of topics/leaflets read by participants was 11.80 (SD = 3.11). In Group 2, who were sent 10 topics/leaflets, the corresponding mean was 9.73 (SD = 0.89). Eighty percent of the women in Group 1 had read all of their information pack compared to 89% in Group 2. Two women (both in Group 1) had not read any of their information pack. Every topic of information had been read at least once by no less than 90% of the participants who received that topic. None of the topics of information were read by considerably fewer participants than any of the other topics. The three accompanying published leaflets were less widely read as each one had not been read by 10-20% of participants.

Most of the women in Groups 1 and 2 had read the information pack more than two weeks ago (n = 47, 47%) with 18 women (18%) reading it 1-2 weeks ago and 34 (34%) in the past week. There were no significant differences between Groups 1 and 2 on when they had last read any of the information pack.

The majority of participants in both groups (60%- 95%) thought that the information included in every topic was at least “a little” new to them with up to 41% regarding most of the information in a particular topic as new (i.e. genetic testing) and up to 18% regarding all the information in a particular topic as new (i.e. HRT).

Forty-five percent of women in Group 1 (n = 23) and 27% in Group 2 (n = 13) had discussed the information in their pack with somebody else. Nine women (18%) in Group 1 and seven (14%) in Group 2 stated that someone else had read the information in their pack. The other people listed as discussing or reading the information pack included husbands, friends, sisters, daughters and mothers.

Only 12 participants (12%) in both groups found any of the topics difficult to understand. The topics that were most frequently found to be difficult to understand were “breast cancer genetics” (n = 8) and “genetic testing” (n = 7).

Similarly, only five women (5%) found any of the topics of information upsetting. The topics found to be upsetting were: breast cancer genetics; genetic testing; options for women with a family history of breast cancer; hormone replacement therapy; diagnosis and treatment of breast cancer (one woman listed two topics as upsetting).

Participants generally found all of the topics of information and leaflets at least a little helpful. Although half of the topics were rated as “not at all helpful” this was only by one or two women. A large proportion of the women (23-45%) rated each topic as “very much helpful”. The three published leaflets were commonly regarded as helpful (a little, quite a bit, very much) with about half of participants (48-54%) who received the particular leaflet rating it as “quite a bit helpful”. Even though each leaflet was rated as “not at all helpful” it was only by 2-10% of participants.

As far as changing or intending to change certain health behaviours were concerned, almost half of Groups 1 and 2 reported becoming or intending to become more breast aware since reading the information pack (Table 6.6).

Table 6.6: Health behaviour change: breast awareness

Being Breast Aware:	Group 1 and Group 2
N	95
<i>Since reading the information pack, I have become more breast aware</i>	20 (21%)
<i>Since reading the information pack, I intend to become more breast aware</i>	25 (26%)
<i>I was already being breast aware</i>	49 (52%)
<i>In spite of reading the information pack, I don't intend to become more breast aware</i>	1 (1%)

Half of the women in Group 1 (n = 24) reported that since reading the information pack they had adopted or intended to adopt a healthier lifestyle (Table 6.7). These women reported that they had already changed or intended to change several different aspects of their lifestyle: increase exercise (n = 22, 92%), healthier diet (n = 17, 71%), increase skin protection from the sun (n = 5, 21%), reduce alcohol intake (n = 3, 13%), stop smoking (n = 2, 8%).

Likewise, over half of the women in Group 1 reported using or intending to use the techniques to relieve their worries about breast cancer (Table 6.8).

Table 6.7: Health behaviour change: healthier lifestyle

Having a Healthier Lifestyle:	Group 1
N	48
<i>Since reading the information pack, I have adopted a healthier lifestyle</i>	4 (8%)
<i>Since reading the information pack, I intend to adopt a healthier lifestyle</i>	20 (42%)
<i>I was already adopting a healthy lifestyle</i>	24 (50%)
<i>In spite of reading the information pack, I don't intend to adopt a healthier lifestyle</i>	0

Table 6.8: Health behaviour change: relieving worry

Ways to Relieve Worries about Breast Cancer:	Group 1
N	46
<i>Since reading the information pack, I have been using the techniques to relieve worry about breast cancer</i>	4 (9%)
<i>Since reading the information pack, I intend to use the techniques to relieve worry about breast cancer</i>	22 (48%)
<i>I was already using techniques to relieve worry about breast cancer</i>	14 (30%)
<i>In spite of reading the information pack, I don't intend to use the techniques to relieve worry about breast cancer</i>	6 (13%)

Twenty-seven percent of participants ($n = 24$) in Groups 1 and 2 thought that they would obtain some of the further reading listed in the information pack. Of these 24 women, seven mentioned that they would look at some of the websites listed, five women wanted to obtain further information about HRT and five women wanted to obtain further information about breast cancer genetics/genetic testing (categories were not mutually exclusive).

Only one woman in Group 1 (1%) and five women in Group 2 (10%) thought that there was any information not included in the pack that they would have liked to know. The topics of information that were thought to be missing by the five women in Group 2 were (the woman in Group 1 did not specify what she thought was missing): more details on genetic testing ($n = 1$), more details on new cancer treatments ($n = 1$), lifestyle ($n = 1$) and contact information for the Ardmillan clinic

(n = 1) (missing data: n = 1). The last two of these topics listed as missing were included in the psychosocial section of the information pack.

Ninety-two percent of Group 1 (n = 44) and 98% of Group 2 (n = 48) thought that the information pack covered their need for information and support. The other types of service that were suggested by the remaining five women (four in Group 2 and one in Group 1) were: genetic testing (n = 1), more detailed information pack (n = 1), information on current breast cancer research and alternative treatments (n = 1) (missing data: n = 2).

6.13.3 Comparison between baseline and post-intervention for each group

6.13.3a Cancer Worry

Table 6.9 presents scores on the CWS for the three groups at baseline and post-intervention for women with complete data. Group 1 ($z = -2.133$, $p = .033$) and Group 3 ($z = -2.449$, $p = .014$) showed a significant decrease in CWS score from baseline to post-intervention. In Group 2, there was no significant change in CWS score.

Table 6.9: Cancer worry scale scores at baseline and post-intervention for participants with complete data

CWS score		Group 1 (n = 50)	Group 2 (n = 49)	Group 3 (n = 49)
<i>Baseline</i>	Median	9.5	9	10
	Range	6-20	6-17	6-17
<i>Post-intervention</i>	Median	9	9	9
	Range	6-16	6-24	6-16

Table 6.10 shows changes in CWS score for each of the three groups. CWS score had decreased for 54% of the women from Group 1, compared to 35% of Group 2 and 45% of Group 3. The median change in CWS score for Group 1 was -1 , representing a decline of one point on the scale. This compared to a median change of 0 in Groups 2 and 3. Changes in the CWS scores from baseline to post-intervention ranged from a reduction of seven points to an increase of five points in Group 1, from a reduction of five points to an increase of 12 points in Group 2 and a reduction of five points to an increase of two points in Group 3.

Examination of changes in individual items of the CWS for Group 3 indicated that the only item to have improved to a level approaching significance was “during the past month, how often have you thought about your own chances of developing cancer?” ($p = .057$). Eleven of the 49 women in this group who had answered this question as “sometimes/often/almost all of the time” at baseline, had responded “not at all or rarely” post-intervention.

Table 6.10: Change in Cancer Worry Scale scores from baseline to post-intervention

Change in CWS scores		Group 1	Group 2	Group 3
Total	N	50	49	49
	Median	-1	0	0
	Range	-7 to 5	-5 to 12	-5 to 2
Decreased	N	27	17	22
	%	54	35	45
	Range of decrease	1-7	1-5	1-5
Same	N	13	16	18
	%	26	33	37
Increased	N	10	16	9
	%	20	33	18
	Range of increase	1-5	1-12	1-2

6.13.3b Objective knowledge of breast cancer risk-related topics

Table 6.11 presents scores on objective knowledge for the three groups at baseline and post-intervention for women with complete data. In Group 1 and Group 2, there was a significant increase in Objective knowledge: total correct ($z = -4.605$, $p = .000$, $z = -5.090$, $p = .000$) and a significant decrease in Objective knowledge: total don't know from baseline to post-intervention ($z = -4.579$, $p = .000$, $z = -5.000$, $p = .000$). In Group 2, there was also a significant decrease in Objective knowledge: total incorrect ($z = -2.210$, $p = .027$). However, there were no significant changes in Group 1 on Objective knowledge: total incorrect. Examination of the individual knowledge items revealed persistent misunderstandings in Group 1 where over half of the group post-intervention still gave the incorrect response (i.e. “Genetic testing: can find mistakes in all the genes that cause an inherited genetic susceptibility to breast cancer”, 58%; “The following are designed to reduce the risk of breast cancer developing: mammography”, 63%; “clinical breast-examination”, 69%; “breast

awareness”, 71%; “Mammography: is proven to be useful for women under 50 with a family history of breast cancer”, 78%). In Group 3, there were no significant changes between baseline and post-intervention on any of the knowledge totals.

Table 6.11: Objective knowledge total scores at baseline and post-intervention for participants with complete data

Objective knowledge		Group 1 (n = 35)	Group 2 (n = 36)	Group 3 (n =38)
Total correct: <i>Baseline</i>				
	Median	15	17	14.5
	Range	6-27	8-35	7-31
	<i>Post-intervention</i>			
	Median	23	27.5	15.5
	Range	3-33	11-36	6-33
Total incorrect: <i>Baseline</i>				
	Median	9	7.5	7.5
	Range	3-18	1-14	1-15
	<i>Post-intervention</i>			
	Median	8	7	9
	Range	2-18	0-13	2-17
Total “don’t know”: <i>Baseline</i>				
	Median	10	11	12.5
	Range	2-23	0-21	1-22
	<i>Post-intervention</i>			
	Median	3	1	11.5
	Range	0-26	0-16	0-25

Tables 6.12, 6.13 and 6.14 shows changes in the three objective knowledge total scores between baseline and post-intervention for each of the three groups.

With reference to changes in the total number of correct responses to the objective knowledge items (Table 6.12), most of the women in Groups 1 and 2 (86% and 94%) had given a greater number of correct responses post-intervention than they had at baseline, compared to only 53% of Group 3. The median changes in total correct scores for Groups 1 and 2 (7 and 8.5) were higher than the median change score of 1 in Group 3, representing a greater improvement in Groups 1 and 2 than in Group 3.

Table 6.13 shows over half of Groups 1 and 2 (51% and 61%) gave fewer incorrect responses post-intervention than at baseline. This compares to only 37% of Group 3. The median change in the total number of incorrect responses was –1 for Groups 1 and 2, representing fewer incorrect responses compared to a median change of 1 in Group 3, reflecting greater incorrect responses.

A large proportion of the women in Group 1 (83%) and Group 2 (92%) gave fewer “don’t know” responses post-intervention than at baseline (Table 6.14). This compares to 61% of Group 3. Although the median changes for all groups represented fewer “don’t know” responses at post-intervention than baseline, the greatest change was in Group 2 (-8.5).

Table 6.12: Change in scores on Objective knowledge: total correct from baseline to post-intervention

Change in scores on Objective knowledge: total correct		Group 1	Group 2	Group 3
<i>Total</i>	N	35	36	38
	Median	7	8.5	1
	Range	-5 to 20	-3 to 20	-7 to 11
<i>Decreased</i>	N	3	1	14
	%	9	3	37
	Range of decrease	1-5	3	1-7
<i>Same</i>	N	2	1	4
	%	6	3	11
<i>Increased</i>	N	30	34	20
	%	86	94	53
	Range of increase	1-20	1-20	1-11

Table 6.13: Change in scores on Objective knowledge: total incorrect from baseline to post-intervention

Change in scores on Objective knowledge: total incorrect		Group 1	Group 2	Group 3
<i>Total</i>	N	35	36	38
	Median	-1	-1	1
	Range	-8 to 7	-7 to 5	-6 to 8
<i>Decreased</i>	N	18	22	14
	%	51	61	37
	Range of decrease	1-8	1-7	1-6
<i>Same</i>	N	6	5	3
	%	17	14	8
<i>Increased</i>	N	11	9	21
	%	31	25	55
	Range of increase	1-7	1-5	1-8

Table 6.14: Change in scores on Objective knowledge: total don't know from baseline to post-intervention

Change in scores on Objective knowledge: total don't know		Group 1	Group 2	Group 3
<i>Total</i>	N	35	36	38
	Median	-5	-8.5	-1
	Range	-20 to 4	-19 to 5	-10 to 6
<i>Decreased</i>	N	29	33	23
	%	83	92	61
	Range of decrease	1-20	1-19	1-10
<i>Same</i>	N	2	1	1
	%	6	3	3
<i>Increased</i>	N	4	2	14
	%	11	6	37
	Range of increase	1-4	1-5	1-6

6.13.3c Breast cancer–specific distress: Impact of Event Scale (IES)

A summary of IES scores for the three groups at baseline and post-intervention for women with complete data is in Table 6.15. In Groups 1 and 2, there were no significant changes between baseline and post-intervention on any of the three IES scores. However, in Group 3 there was a significant decrease in scores on the intrusion subscale from baseline to post-intervention ($z = -2.248$, $p = .025$) but no significant changes on avoidance and total IES scores.

Table 6.15: IES scores at baseline and post-intervention for participants with complete data

IES scores		Group 1	Group 2	Group 3
Intrusion: <i>Baseline</i>	N	9	13	16
	Median	10	7	6.5
	Range	0-33	0-25	0-27
	Post-intervention			
	Median	9	11	4
Avoidance: <i>Baseline</i>	Range	0-12	0-35	0-25
	N	9	10	15
	Median	9	7.5	10
	Range	0-26	0-23	0-30
	Post-intervention			
IES total : <i>Baseline</i>	Median	8	17.5	7
	Range	0-17	0-40	0-30
	N	8	10	15
	Median	18.5	14	14
	Range	0-59	2-47	0-51
Post-intervention	Median	16.5	27.5	11
	Range	0-27	0-75	0-51

6.13.3d General Psychological Distress: GHQ-12

Table 6.16 presents GHQ-12 total scores and the proportion of participants suffering from “case-level” distress in the three groups at baseline and post-intervention for participants with complete data. There were no significant changes in any of the three groups on GHQ-12 total or “case-level” distress between baseline and post-intervention. However, the number of GHQ-12 cases in Group 1 decreased to a level approaching statistical significance ($p = .057$).

Table 6.16: GHQ-12 total scores and “case-level” distress at baseline and post-intervention for women with complete data

GHQ-12		Group 1 (n = 51)	Group 2 (n = 48)	Group 3 (n =49)
Total score: <i>Baseline</i>				
	Median	1	0	0
	Range	0-11	0-12	0-12
	<i>Post-intervention</i>			
<i>Post-intervention</i>	Median	0	0	0
	Range	0-11	0-12	0-10
“Case-level” distress: <i>Baseline</i>				
	Case	15 (29%)	10 (21%)	17 (35%)
	Non-Case	36 (71%)	38 (79%)	32 (65%)
	<i>Post-intervention</i>			
<i>Post-intervention</i>	Case	7 (14%)	7 (15%)	12 (25%)
	Non-Case	44 (86%)	41 (85%)	37 (76%)

6.13.3e Appraisal *

A summary of perceived risk, perceived likelihood and perceived control over developing breast cancer for the three groups at baseline and post-intervention for participants with complete data is shown in Table 6.17. There were no significant changes within the groups on any of the appraisal measures apart from a significant decrease in perceived likelihood for Group 2 ($p = .039$) and a significant increase in perceived control ($p = .004$) for Group 1 (within-group differences on perceived risk could not be tested due to the small numbers in some categories).

* Although, individual changes in perceived risk and perceived likelihood between baseline and post-intervention were not calculated given the exploratory nature of this analysis, the data were checked for extreme shifts. Participants who altered their perceived risk or perceived likelihood between baseline and post-intervention did not change by more than one of the original categories.

Table 6.17: Appraisal variables at baseline and post-intervention for women with complete data

Appraisal		Group 1	Group 2	Group 3
Perceived risk of developing breast cancer:*	N	50	48	51
	<i>Lower than</i>	1 (2%)	0	0
	<i>The same as</i>	4 (8%)	4 (8%)	0
	<i>Slightly higher than</i>	35 (70%)	31 (65%)	37 (73%)
	<i>Much higher than</i>	10 (20%)	13 (27%)	14 (28%)
	<i>Lower than</i>	0	0	0
	<i>The same as</i>	6 (12%)	3 (6%)	2 (4%)
	<i>Slightly higher than</i>	37 (74%)	35 (73%)	36 (71%)
	<i>Much higher than</i>	7 (14%)	10 (21%)	13 (26%)
Perceived likelihood of developing breast cancer:	N	47	45	50
	<i>Unlikely</i>	13 (28%)	12 (27%)	16 (32%)
	<i>Likely</i>	34 (72%)	33 (73%)	34 (68%)
	<i>Unlikely</i>	16 (34%)	19 (42%)	14 (28%)
	<i>Likely</i>	31 (66%)	26 (58%)	36 (72%)
Perceived control over developing breast cancer:	N	50	48	51
	<i>None at all</i>	15 (30%)	20 (42%)	16 (31%)
	<i>Some</i>	35 (70%)	28 (58%)	35 (69%)
	<i>None at all</i>	6 (12%)	14 (29%)	18 (35%)
	<i>Some</i>	44 (88%)	34 (71%)	33 (65%)

* in relation to the general population.

6.14 Discussion

6.14.1 Participants

Compliance with the study was good as the participation rate for completing both questionnaires was 73%. There were no statistically significant differences between the participants at baseline and the non-participants on several sociodemographic and coping style measures. This was despite the fact that the participants were self-selected as they had all expressed an interest in at least one of the intervention options listed in the cross-sectional questionnaire study. However,

the results suggest that the small number of participants who dropped out of the study may have been biased with respect to high levels of intrusive and avoidant thoughts about breast cancer. This suggests that these women may have dropped out of the study in an effort to reduce their high levels of breast cancer-specific distress. Therefore, the post-intervention results should be interpreted with caution (this is further discussed in Section 6.14.6, page 189).

At baseline, there were no significant differences between the three groups apart from on the coping style variable “Cognitive uncertainty” (CU) that was extracted from the cross-sectional questionnaire study. CU is a style of coping with uncertainty through cognitive means: “CU assesses the need to plan ahead of time, and to seek clarification and gather information, as strategies for avoiding ambiguity” (Greco & Roger, 2001). Group 3 scored significantly higher at baseline on CU than the other two groups. In addition, a positive correlation that was approaching significance was observed between CU and baseline cancer worry. This may have affected outcome of Group 3 which will be discussed in Section 6.14.2b, page 180.

6.14.2 Aim 1: To determine the impact of a psychoeducational written intervention on cancer worry (primary outcome) and objective knowledge of breast cancer risk-related topics (secondary outcome).

6.14.2a Hypothesis 1: The addition of Scientific + Psychosocial Written Information to standard care (Group 1) will reduce cancer worry to a greater extent than the addition of Scientific Written Information alone (Group 2).

At baseline, the median Cancer Worry Scale (CWS) score for the total sample (median = 9) was slightly lower than for those reported in women prior to attending breast cancer genetic risk counselling (Watson et al, 1998: median = 11; Hopwood et al, 2001: median = 11) and 2-21 months post-counselling (Hopwood et al, 2001: median = 11). This may suggest that cancer worry generally declines in the years following genetic risk counselling. However, further longitudinal research would be needed to assess the course of cancer worry in these women over a period of years. It is understandable that these women would be worried about breast cancer given the uncertainty associated with having a family history, however 54% of participants at baseline reported that worrying about cancer was a problem for them.

The findings of the study provide evidence to support hypothesis 1. There was a statistically significant decrease in the cancer worry of Group 1 from baseline to post-intervention and no corresponding decrease in the cancer worry of Group 2. On average, CWS scores decreased by one point in Group 1 and stayed the same in

Group 2. For over half of the participants in Group 1, CWS scores had decreased between baseline and post-intervention compared to 35% of Group 2. The lack of impact of the scientific topics of information alone on cancer worry suggests that the psychosocial topics played a key role in the reduction of cancer worry in Group 1. The results contrast those of a previous written intervention in American women with a family history of breast cancer where neither general psychological nor breast cancer-specific distress were significantly reduced (i.e. Gagnon et al., 1996).

Although the cancer worry of Group 1 significantly decreased, the reduction may be slightly conservative. Nearly a quarter of Group 1 reported becoming more breast aware as a result of reading the information pack. This change in behaviour may have prompted an increase in breast-cancer specific distress as breast awareness could act as a cue to worry as participants in the telephone focus group study have described.

The results suggest that psychosocial self-help information in the form of techniques for coping with or reducing worry and advice on maintaining a healthy lifestyle can effectively reduce cancer worry in this group of women. However, further research would be needed to identify which specific aspects of the psychosocial topics make the greatest contribution to the reduction in cancer worry.

In addition, the results did not provide any evidence that the information pack significantly increased cancer worry (there was limited upset reported which is discussed in Section 6.14.4, page 185). However, for 20% of Group 1 CWS scores were found to increase up to 5 points between baseline and post-intervention and to increase up to 12 points for a third of Group 2. This particularly raises concern regarding the results for Group 2. These suggest that providing scientific information about familial risk of breast cancer without the addition of psychosocial information to help control worry, may result in elevated breast cancer-specific distress for a substantial proportion of women. However, the clinical importance of these changes in cancer worry remains unclear until further research on this scale is undertaken, including deriving clinical thresholds.

6.14.2b Hypothesis 2: Scientific Written Information in addition to standard care (Group 2) will reduce cancer worry to a greater extent than standard care alone (Group 3).

The results of this study do not support the predictions of hypothesis 2. The cancer worry of Group 2 did not significantly decrease from baseline to post-intervention, but there was a significant decrease in the cancer worry of Group 3. Although the median change in CWS scores of both groups indicated no difference

in cancer worry from baseline to post-intervention, CWS scores had decreased for 45% of Group 3 compared to 35% of Group 2.

This finding that the control group (Group 3) experienced a greater reduction in cancer worry may be the result of this group not being contacted about the study for four weeks after returning the baseline questionnaire. As this group's involvement in the study during these four weeks was at a minimum, they may have experienced fewer cues to remind them about breast cancer. Indeed, the only CWS individual item to have decreased to a level of near statistical significance was the frequency they had thought about their own chances of developing cancer in the past month. We have previously described the experiences of women at increased risk of breast cancer concerning increased anxiety prompted by a variety of breast cancer cues (Appleton et al., 2000).

Another explanation for the decrease in the cancer worry of Group 3 may be related to the significantly higher score on the Cognitive Uncertainty coping style subscale that was observed at baseline. This means that this group had a stronger tendency to cope with uncertain situations through cognitive means such as information seeking. It may be possible that towards the end of the study period the group were anticipating receiving the information pack (for ethical reasons, they were told when randomised that they would be offered the information pack at the end of the study). As we had observed a positive correlation between scores on the Cognitive Uncertainty subscale and cancer worry at baseline, cancer worry may have decreased as a result of anticipating receiving the information pack.

In addition, there were two women in Group 3 (the control group) who had read information related to familial risk of breast cancer over the study period. As it is possible that reading this information may have prompted an increase in breast cancer-specific distress, the results on these measures still may be slightly conservative.

6.14.2c Hypothesis 3: Written Information in addition to standard care (Groups 1 and 2) will improve objective knowledge of breast cancer risk-related topics to a greater extent than standard care alone (Group 3).

Objective knowledge of breast cancer risk-related topics at baseline was generally poor. On average participants at baseline gave the correct response to less than half of the questions, the incorrect response to about a quarter of the questions and didn't know the answer to about a third of the questions. This was despite the fact that the participants were a highly educated group (51% were educated or trained after age 18) as is commonly found in health screening populations (Rimer et al.,

1996). Other studies that have objectively assessed knowledge relating to breast cancer genetics in women with a family history of breast cancer have reported varying levels of knowledge (e.g. Lerman et al., 1996; Wonderlick & Fine, 1997; Cull et al., 1998; Bluman et al., 1999; Meiser et al., 2001a & b). Persistent errors in understanding of certain issues were reported in British first-time attendees of genetic risk counselling for breast cancer, despite receiving a video about breast cancer genetics and screening (Cull et al., 1998). Therefore the baseline results alone support the need for information, to update that which these women may have been given when they first attended the familial breast cancer clinic several years previously.

The results of this study provide evidence to support hypothesis 3. Objective knowledge of breast cancer risk-related topics significantly improved in Groups 1 and 2, who received different versions of the information pack, but remained unchanged in Group 3 (the control group). In Group 1, there was a significant increase in the total of correct responses and a significant decrease in the total number of “don’t know” responses from baseline to post-intervention. In Group 2, there was a significant increase in the total of correct responses and significant decreases in the total of incorrect and “don’t know” responses from baseline to post-intervention. Objective knowledge had improved (i.e. more correct responses, fewer incorrect responses and fewer “don’t know” responses) for the vast majority of women in Groups 1 and 2. In Group 3, there were no significant changes between baseline and post-intervention on any of the objective knowledge total scores.

Although there was a slight decrease in the number of incorrect responses of Group 1 between baseline and post-intervention, it was not found to be statistically significant. This may be due to receiving the psychosocial as well as the scientific topics of information. As these women were sent more material to read and absorb than Group 2, it is possible that the full information pack was too lengthy to be effectively retained. This is also reflected in the fact that Group 2’s knowledge seemed to improve to a greater extent than Group 1 as shown by the greater median change in scores than Group 1 and differences in the distribution of these changes. Although we didn’t received any feedback from Group 1 that suggested there was too much information in the pack, a smaller proportion of the women in Group 1 reported reading the whole of the information pack than Group 2. Future research could investigate the effectiveness of written information of varying detail and length to enable the development of an intervention that is of optimal benefit to these women.

The persistent misunderstandings of Group 1 where over half of the group still gave the incorrect response post-intervention were concerning genetic testing (“Genetic testing: can find mistakes in all the genes that cause an inherited genetic susceptibility to breast cancer”) and screening (“The following are designed to reduce the risk of breast cancer developing: mammography, clinical breast-examination, breast awareness”; “Mammography: is proven to be useful for women under 50 with a family history of breast cancer”). These findings highlight areas where the information pack could perhaps have provided more emphasis and where future interventions may choose to focus.

6.14.3 Aim 2: To explore the impact of a psychoeducational written intervention on breast cancer specific-distress (as measured by the Impact of Event Scale), generalised psychological distress (as measured by the GHQ-12) and appraisal (as measured by perceived risk, perceived likelihood and perceived control).

There was no evidence to suggest that the information pack caused a significant increase in intrusive or avoidance thoughts about breast cancer risk. Although it was not found to be statistically significant, the median IES scores for Group 2 had increased substantially. Although the clinical significance of the size of these changes remains unclear, it still raises concern about the impact of providing scientific information about breast cancer in the absence of advice about dealing with worry.

In Group 3, there was a statistically significant decrease in intrusive thoughts about breast cancer risk from baseline to post-intervention. This finding mirrors the decrease in cancer worry in this group and again may be due to the fact that the group was not contacted about the study during the four weeks between questionnaire assessments.

The results of the study do not provide any evidence that general psychological distress was significantly increased by the information pack. Moreover, the number of GHQ-12 cases in Group 1 decreased from baseline to post-intervention at a level approaching statistical significance. This suggests that the addition of the self-help psychosocial information helped to reduce general psychological distress to a certain extent as well as cancer worry.

Although between- and within-group differences on perceived risk were not tested due to the small numbers in some of the categories, the data shows that in Group 1, fewer women post-intervention perceived their risk to be in the extreme categories (i.e. lower than or much higher than the general population) than at

baseline. It is possible that this shift reflects a general improvement in the accuracy of the perceived risk of this group. Although this would require further investigation, it may be due to improved scientific knowledge such as concerning breast cancer genetics or risk factors for the disease.

In Group 2, there was a significant decrease in the perceived likelihood of ever developing breast cancer from baseline to post-intervention. Perceived likelihood had decreased for eight women in this group (from “likely” to “unlikely”). One possible explanation for this result could be that the information pack had improved the accuracy of their perceived risk. However, we could not appropriately assess this accuracy as we couldn’t assume that the objective breast cancer risk the participants had most recently been given at the clinic, were the same as the updated risk estimates we used to describe the participants in this study. Further research would be needed to investigate the role of the accuracy of risk perception both as a moderator and outcome of psychoeducational intervention. Although perceived likelihood had decreased for this group, we found no corresponding decrease in breast cancer-specific or generalised distress. Research in first-time attendees of genetic risk counselling for breast cancer has shown that a decrease in perceived risk is not directly associated with a reduction in psychological distress (Cull et al., 1999).

In Group 1, there was a statistically significant increase in perceived control over ever developing breast cancer from baseline to post-intervention. Perceived control had increased for nine women in this group (for seven women from “none at all” to “a bit”, for two women from “none at all” to “moderate”). Although, there was also an increase in perceived control in Group 2, it did not reach statistical significance. These results show that the addition of the self-help psychosocial information can increase perceived control to a greater extent than the scientific information alone. These results support our previous qualitative findings where women with an increased risk of breast cancer described how adopting a healthier lifestyle had enhanced their feelings of control over their risk of breast cancer: “...all these things help you to feel you are in control of the situation rather than the situation is in control of your life so I think it is very important to do things, positive things, to make you feel you are doing all you can, you know, not to have it (breast cancer)” (Appleton et al., 2000). The increase in perceived control may also help to explain the decrease in cancer worry and general psychological distress in Group 1. It has been suggested that “low levels of perceived control may increase vulnerability to cancer-specific distress” in women with a family history of breast/ovarian cancer (Audrain et al., 1997). Taylor et al. (1984) has shown that in breast cancer patients

perceived control over breast cancer (both in terms of internal and external control) was significantly associated with good adjustment to breast cancer.

6.14.4 Aim 3: To evaluate the acceptability of the psychoeducational written intervention for women living with an increased risk of breast cancer.

Both versions of the information pack (scientific/scientific and psychosocial) were generally found to be highly acceptable to participants. This was supported by the high participation rate for the study and the high demand for the full information pack after the post-intervention assessment. Participants' comments were extremely positive about the information packs: "I feel that the information pack has been and will continue to be a vital source of information and advice for me on the subject of breast cancer and all the related issues" (woman from Group 1).

The information packs were well read by participants. At least 80% of Groups 1 and 2 read all of the topics and leaflets they were sent at least once. Each topic of information was read by at least 90% of the women who had been sent it, whereas the accompanying leaflets were less well read (e.g. 20% of Group 1 did not read the "How to...Stop Worrying" leaflet). Only two women (both in Group 1) had not read any of the information pack (this is discussed in Section 6.14.5, page 187).

The vast majority of participants found all of the topics and leaflets helpful. For the majority of women, at least some of the information included in each of the topics was new to them. Therefore the information packs did not simply repeat the information these women may have been given at the familial breast cancer clinic several years previously, but provided them with new pieces of information. Almost half of Group 1 and one third of Group 2 had discussed the information in their pack with their husband, friends or other family members. Slightly more women from Group 1 had given their information pack to their husband, friends or other family members to read. These differences may reflect the wider relevance of the psychosocial topics of information for other family members.

Only a small number of people ($n = 12$) had found any of the topics difficult to understand, of which the breast cancer genetics and genetic testing topics were most frequently listed. As one woman in Group 2 commented: "I felt that this was pitched at the correct level for a non-medically minded individual. A good balance of information and not too technical or lengthy. Very user friendly. I, for one, would have appreciated such a pack on referral to the clinic".

Only five women had found any of topics of information upsetting, of which the diagnosis and treatment of breast cancer topic was listed twice as often as any of

the other topics. Of the five women who were contacted regarding their upset in relation to reading the information pack, three responded, of whom two were willing to discuss their upset. For one of the women, receiving the information pack had acted as a cue to worrying about breast cancer, but she thought no more so than watching a television programme about breast cancer. For the other woman, the information pack had raised concerns about genetic testing and she was subsequently contacted by a genetic breast care nurse from the Ardmillan clinic to discuss these concerns.

The impact of the information pack on changes in or intention to change particular health behaviours was good. This is encouraging since behavioural change was not the main focus of this brief intervention. Nearly half of participants had or intended to become more breast aware as a result of reading the information pack. Similarly half of participants had or intended to adopt a healthier lifestyle where the majority of these women were focusing on increasing their exercise and having a healthier diet. Over half of participants had or intended to use the techniques to relieve worry about breast cancer. However, these results should be interpreted with caution as we did not take into account the social desirability of indicating an improvement in health behaviour.

In addition, an intention to change a particular health behaviour is not necessarily realised: "Although intention to change is associated with an increased likelihood of doing so, it predicts only about 30% of the variance in behavioural change (Marteau & Lerman, 2001). Therefore, further research could investigate the addition of a follow-up intervention to help participants realise their good intentions. The interventions most effective in changing behaviour tend to focus on reinforcing people's beliefs about their ability to alter their behaviour and risk reduction (Marteau & Lerman, 2001). In this study, given the lack of scientific evidence that changing certain health behaviours can reduce the risk of breast cancer, the intervention promoted health behaviours that reduce general health risks whilst also providing practical self-help information in changing health behaviours. Future interventions that aim to change health behaviours in this population could provide similar information, but perhaps with more emphasis and detail than we have provided in the present intervention.

The results show that the information pack generally met the needs of this group of women. As one participant at baseline stated: "I feel that as a woman under 50 years with a family history of breast cancer, I receive no additional information that might increase my knowledge and decrease my anxieties". Only a few participants thought there was information missing from the pack that they would

have liked to know (most of these women were in Group 2 and the missing topics of information were included in the psychosocial component of the other information pack). As over 90% of participants thought that the information pack covered their need for information and support, this suggests that this type of psychoeducational intervention may be sufficient in meeting these needs.

6.14.5 Methodological issues

There are a number of methodological issues with the study concerning the participants, measures and analysis that should be considered when interpreting the results.

Regarding the participants, two observations were noted that may have slightly affected the results. Firstly, one participant, who stated she was an oncology health professional (in Group 2), only gave an incorrect response to one of the knowledge questions at baseline, leaving little room for an improvement post-intervention. Therefore the improvement in knowledge for this group may be slightly conservative. Secondly, nine of the participants (6%) at baseline were estimated to have a low risk of breast cancer. As this rendered the sample more heterogeneous with respect to their objective risk of breast cancer, the results particularly concerning perceived risk and psychological distress may have been affected. The familial breast cancer clinic was likely to be in the process of discharging these women as they were now not deemed to be at sufficiently increased risk of breast cancer to warrant clinical surveillance before the age of 50.

Despite the fact that the objective knowledge measure was developed specifically for this study by a multidisciplinary group, it was an ad hoc instrument and was not subjected to psychometric testing. At the time of designing the study, using a study-specific measure that assessed the key points of information included in the scientific topics was deemed more appropriate than using any of the existing measures of objective knowledge (e.g. BCHK scale – Ondrusek et al., 1999). Use of an existing scale or our knowledge measure (if subjected to validation) may be appropriate on first time attendees of a familial breast cancer clinic to highlight areas where knowledge is lacking to highlight an appropriate intervention. A few participants did not understand some of the knowledge questions at baseline. Three participants were not sure whether the questions about procedures designed to reduce the risk of breast cancer developing, referred to breast cancer starting or spreading. Some participants did not understand other terms in the objective knowledge items:

genetic mistake, the genes BRCA1 and BRCA2 and prophylactic surgery. These terms should perhaps have been further clarified in the questions.

As the data were analysed on an intention-to-treat basis, all participants were included in the analysis even if they had not read all of the information pack. There was a minority of women in Groups 1 and 2 who had only read certain topics or leaflets in the information pack. Reasons that were given for this included a recent bereavement from cancer. An additional explanation may be the variation between participants in the relevance of some of the topics (e.g. the HRT topic was more relevant to the older women in the group). Only two women (both from Group 1) had not read any of the information pack. One of these women said she couldn't face reading it at the moment but would when her life had quietened down and the other woman did not give a reason. Given that not all of the participants had read all of the information they were sent, the reduction in cancer worry in Group 1 and improvement in knowledge for Groups 1 and 2 are likely to be conservative estimates. In addition, some of the women who indicated they had not read a particular topic, did rate that topic for example on its helpfulness. It is likely that these women may have glanced at this topic whilst looking through the information pack, but may have felt they hadn't actually read it in detail. Future studies could assess the degree to which participants read an information pack for example from skimming through the topic headings to reading everything in detail. It would then be possible to assess if the extent to which participants read the information pack was related to a reduction in cancer worry or if simply providing information reassured the women and reduced their cancer worry regardless of whether they actually read the information.

In regard to widely accepted criteria for the design and reporting of randomised controlled trials, this study meets the majority of criteria of the CONSORT (Consolidated Standards of Reporting Trials) statement (Moher et al., 2001). In particular, details on the following aspects were reported: a description of the interventions administered to each group; specific objectives and hypotheses, clearly defined key outcome measures, details of sample size calculations and randomisation, the number of participants through each stage of the trial, methods of analysis. However, due to resource constraints of the study only one researcher was involved in the study procedure. This meant that, in contrast to CONSORT guidelines, the same researcher was involved in the development of the intervention, the recruitment of participants, randomisation and assessment of study outcomes. In addition, although participants were randomised using a restricted random permuted blocks method, the researcher was not blind to which group each participant had

been assigned. Although these factors are unlikely to have influenced the results of this particular trial, it would nevertheless have been desirable to have a second researcher involved in the study procedure to prevent any potential bias.

6.14.6 Study limitations

A number of limitations with the present study were noted regarding missing data, the clinical significance of findings, lack of long-term follow-up, Impact of Event Scale and clinical appointment data.

Missing data pose a particular challenge to the interpretation of outcomes in a randomised controlled trial. Data may be missing at random or they may represent informative censoring (i.e. a greater proportion of participants dropped out of one group compared to another/there is a consistent reason for participant drop-out). In this study a similar number of participants dropped out from each of the three groups between baseline and post-intervention. However, comparison of those women who dropped out and those who completed the study revealed potential differences in levels of intrusive and avoidant thoughts about breast cancer risk. This means that the complete data used to evaluate the effect of the intervention may be biased with respect to scores on these measures and therefore the results should be interpreted with caution.

Although clinical thresholds have not yet been derived for the Cancer Worry Scale, the results do suggest that the statistically significant reduction in the cancer worry of Group 1 is likely to have some clinical significance. The vast majority of participants found the worry about breast cancer topic to be helpful and it had prompted many of the women to use or intend to use the suggested techniques to relieve worry about breast cancer. It would be essential for further work to identify clinical thresholds on this measure to aid the identification of worried individuals and to measure the clinical effectiveness of associated interventions. Similarly, the interpretation of the objective knowledge results did not benefit from reference data to indicate the clinical significance of improvements. This was an ad hoc instrument, where items were simply summed to give total scores. Improvements in the objective knowledge total scores ranged greatly between individuals. However, it could be argued that even giving the correct response to only one more item post-intervention than at baseline represents a worthwhile improvement in the knowledge of breast cancer-risk-related information.

It may have been desirable to have another follow-up assessment in this study several months later, to discover if any of the short-term improvements in the key

outcomes were sustained. Although a long-term follow-up was outside the scope of this study, this should be incorporated into future research.

Only a minority of participants, who had thought about the risk of breast cancer in the past week, completed the Impact of Event Scale at baseline (43.8%) and post-intervention (34.7%). Therefore, the results of this scale should be interpreted with caution as they do not reflect data from the whole sample.

The participants were originally asked at baseline and post-intervention if they had attended the clinic in the last two weeks or if they had an appointment in the next two weeks. However, this data was not analysed as a subset was found to be unreliable when checked with clinic records and it was outside the scope of this study to collect clinic appointment data from case notes. As our previous research has suggested it is likely an imminent or recent clinic appointment acts as breast cancer cue to prompt an increase in thoughts and worries about breast cancer (Appleton et al., 2000). Such breast cancer cues are likely to have affected an individual's level of breast cancer-specific distress and their response to the information pack. Future longitudinal studies in this area need to identify and collect reliable clinical appointment data and investigate the relationship between this type of breast cancer cue and an individual's levels of psychological distress.

6.14.7 Clinical implications and future research

This study supports the value of a scientific and psychosocial information pack in providing up-to-date information related to familial risk of breast cancer for long-term attendees of a familial breast cancer clinic.

However, the results indicate several ways in which the intervention could be improved. Although the information pack reduced cancer worry and improved knowledge, the results highlighted some persistent misunderstandings about genetic testing and breast cancer screening. These areas in the information pack could be expanded or further clarified in an attempt to improve knowledge in these areas. Future studies could choose to include psychosocial self-help information about how to cope with bereavement (recent or not) as cancer worry is likely to be related to the experience of losing a close relative to breast cancer: as one woman in the study commented "I can't relieve the worry as three of my sisters have died of cancer".

There are a number of ways in which the information pack could be incorporated into clinical services these women are already receiving. The information pack could be used routinely as part of clinical practice to complement and expand on verbal information provided by the clinician. The information pack

could be regularly updated and posted to participants or given to them when they attend the clinic. However, one disadvantage of producing this type of information pack is that it will require frequent updating and reprinting. A better alternative to producing paper copies may be to place the information on a web page that is both easy to update and access. At the time of designing the intervention study we decided not to set up the information pack as a web page initially for several reasons: we were responding to a specific need for written information; we had not received a specific request for a web page; we did not want to limit participants to only those with Internet access (less than half of participants in our previous qualitative study had access to the Internet). Although we would expect access to the Internet to be more widely available now, it may still be necessary to check that the intended audience had Internet access otherwise a paper copy of the information could be issued. Women who are currently attending for genetic risk counselling are likely to receive more standardised and detailed information than the women in this study received when they first attended the clinic several years ago. However, there is still potential value in modifying this information pack specifically for first time attendees to complement the information they are given by the clinicians and include psychosocial information of which they may not have discussed. Likewise, although information pack was developed for women attending a specific familial breast cancer clinic, it could easily be adapted to be applicable to other clinics in the U.K or internationally.

Chapter 7: General Discussion

7.1 Review of the rationale for the current work

At the time of starting the current body of work, growing numbers of women with a family history of breast cancer were being referred for genetic risk counselling. A substantial proportion of those women were identified as being at increased risk of developing breast cancer. Genetic testing was initially expected to be widely available and informative for all of these women. However, it became apparent that for the foreseeable future genetic testing would not be informative for the majority of women at increased risk of breast cancer. In the absence of proven methods to prevent or reduce breast cancer, the clinical management of these women focused primarily on breast cancer screening.

It remains the case today that large numbers of young women are attending familial breast cancer clinics on a regular basis for clinical surveillance. These women are faced with multiple uncertainties regarding their personal risk of developing breast cancer and the effectiveness of risk management strategies. They are likely to have to live with the knowledge of their increased risk of breast cancer for the rest of their lives and face the prospect of years of clinical surveillance. Over the years that they may attend a familial breast cancer clinic, their estimated risk of breast cancer may be adjusted in response to their increasing age or changes in their family history. Although their risk of developing breast cancer due to an inherited susceptibility decreases as they get older, their risk of sporadic breast cancer increases with age. Alterations in the clinical services that are offered to these women may reflect both changes in risk and clinical resources. Given this long-term situation full of uncertainty, the potential for adverse psychosocial effects on these women was clear.

A review of the literature on the psychosocial outcomes of genetic risk counselling for breast cancer revealed that research to date had only assessed participants up to 25 months post-counselling (i.e. Evans et al., 1994; Cull et al., 1999; Schwartz et al., 1999a; Watson et al., 1999; Hopwood et al., 2001; Meiser et al., 2001b; Bish et al., 2002). A limited number of studies had conducted cross-sectional surveys of women at increased risk of breast cancer who were maintained on regular clinical surveillance (i.e. Kash et al., 1992; Valdimarsdottir et al., 1995; Lloyd et al., 1996; Zakowski et al., 1997, 2001). Both bodies of research have found that a substantial number of healthy women with a family history of breast cancer were experiencing significant levels of general psychological and breast cancer-

specific distress. However, little was known about the longer-term psychosocial consequences of living with an increased risk of breast cancer. It was apparent that there was a lack of published research in women at moderate or high risk of breast cancer who had been receiving regular clinical surveillance for a number of years and who were not eligible for genetic testing or prophylactic surgery.

Chronic psychological distress in these women would have important implications for the individuals concerned, their families and the clinical services they receive.

Research has already shown that high levels of psychological distress are associated with non-adherence to mammography (e.g. Lerman et al., 1993), clinical breast-examination (e.g. Kash et al., 1992) and breast self-examination (e.g. Kash et al., 1992). If these methods of breast cancer screening are proven to be effective in young women at increased risk of the disease, chronic distress could interfere with the early detection of breast cancer, thus affecting an individual's prognosis if they are diagnosed with the disease.

Apart from the likely negative psychosocial impact on the family of having a relative who is chronically distressed, these women may represent maladaptive role models for the next generation of their family. For example, their daughters and granddaughters are also likely to face living with an increased risk of breast cancer and may be influenced by how their relative coped when in a similar situation.

These women could also place additional demands on clinical services they receive, that are already under pressure from growing numbers of referrals. Chronically distressed women may miss their routine appointments or request numerous appointments.

Given the lack of knowledge about the long-term psychosocial effects of genetic risk counselling for breast cancer in the current literature, the absence of routine psychosocial services and the far-reaching implications of psychological distress in this group of women, a need for further research was highlighted.

This thesis presented a series of three studies to investigate the psychosocial effects of living with an increased risk of breast cancer in women who had undergone genetic risk counselling and had subsequently been receiving regular clinical surveillance for at least two years. The initial qualitative study aimed to explore the important issues for these women using the novel methodology of telephone focus groups. The second study, a larger quantitative cross-sectional survey, tested and expanded on some of the main findings from the previous study. A psychoeducational written intervention was then developed to meet the needs of these women and evaluated in a randomised controlled trial.

7.2 Summary of main findings

7.2.1 Telephone focus group study

Qualitative analysis of the seven telephone focus groups revealed six key issues concerning the psychosocial effects of living with an increased risk of breast cancer: (1) psychological adaptation, (2) behavioural adaptation, (3) family issues, (4) clinical surveillance, (5) provision of information and (6) peer support.

These results provided qualitative evidence of between- and within-individual differences in terms of anxiety and distress. Participants described experiencing varying degrees of anxiety and distress, with a subset reporting high levels of breast cancer-specific distress. The impact of breast cancer cues (e.g. approaching the date of a routine appointment at the familial breast cancer clinic) varied between participants with some women becoming more distressed in response to these cues. In addition to the impact of breast cancer cues, differences in the levels of anxiety and distress could be due to variations in a number of factors including experiences of breast cancer in the family, beliefs about the disease and perceived risk of breast cancer.

A number of important internal and external coping resources were described including positive cognitions, knowledge about breast cancer-related issues, clinical surveillance and family members. There was qualitative evidence of between- and within-individual variation in the coping strategies adopted which included cognitive strategies such as avoidance and behavioural strategies such as reassurance seeking and health behaviours.

There was a common need for information related to familial risk of breast cancer which was confirmed by the results of the feedback questionnaire: all 25 participants reported that they would like to be provided with up-to-date information on a variety of scientific and psychosocial topics related to familial risk of breast cancer.

This study highlighted a number of possible directions for the subsequent study including further assessment of needs for information and support, investigation of psychological distress both between- and within-individuals, assessment of coping strategies and their role in adapting to living with an increased risk of breast cancer. The main findings that were chosen to be further explored were the needs for information and support and between-individual variation in levels of psychological distress. These findings were selected on the basis that requiring further data in these areas would enable a response to these women's needs, through

the development of an appropriate intervention. Although the other findings raised by the telephone focus group study were not subjected to further investigation by the current body of work, they still warrant more detailed exploration.

7.2.2 Cross-sectional study

The cross-sectional survey of 249 women living with an increased risk of breast cancer tested and expanded on some of the main findings of the telephone focus group study.

The prevalence of probable psychiatric morbidity (26%) and levels of breast cancer-specific distress were similar to that reported in the literature in women with a family history of breast cancer who had more recently attended genetic risk counselling. This suggests that there may not be a cumulative effect over time on levels of psychological distress in women living with an increased risk of breast cancer. However this finding also indicates that any increase in levels of distress experienced a few months after genetic risk counselling may be sustained during the subsequent years. In addition, worries among participants about issues relating to breast cancer risk were extremely common, suggesting that these were not the type of worries that could easily be resolved even over a period of years.

The results provided mixed degrees of support for the study hypotheses.

As predicted, greater perceived likelihood of developing breast cancer and a higher Monitoring coping style were related to worry about breast cancer risk-related issues, lower satisfaction with social supports was related to general psychological distress and a higher Emotional Uncertainty coping style was related to general and breast cancer-specific distress. In addition to these predicted factors, several other exploratory variables were found to contribute to the prediction of general psychological or breast cancer-specific distress: having a psychiatric history, lower educational level and not being married or living with a partner.

However, there was no support for the hypotheses that perceived control over developing breast cancer or the difference between age of their mother at diagnosis of breast cancer and the current age of the woman were related to distress. Likewise, there was no evidence of a relationship between a Monitoring coping style and intrusive thoughts about breast cancer.

The findings of this study confirmed a widespread need for up-to-date information related to familial risk of breast cancer. Over 90% of participants were interested in receiving information about at least one scientific or psychosocial topic.

There was an overall preference (85%) for the information to be presented in a written format rather than a group meeting or telephone discussion group.

7.2.3 Randomised controlled trial

A psychoeducational intervention, consisting of written information on scientific and psychosocial topics related to familial risk of breast cancer, was developed to meet the needs of these women.

The results of a randomised controlled trial of the intervention in 151 women living with an increased risk of breast cancer provided some support for the study hypotheses. The information pack containing both scientific and psychosocial topics of information significantly reduced cancer worry and improved objective knowledge of scientific issues related to familial risk of breast cancer. The information pack that only contained the scientific topics of information significantly improved knowledge whereas no improvement in knowledge was observed in the control group who did not receive any information.

In contrast with the hypotheses, the information pack that only contained the scientific topics did not significantly reduce cancer worry and there was a significant decrease in cancer worry and intrusive thoughts about breast cancer in the control group.

There was no evidence that either version of the information pack significantly increased general psychological or breast cancer-specific distress. The information pack containing both scientific and psychosocial topics of information significantly increased perceived control over developing breast cancer. The information pack that only contained the scientific topics of information significantly decreased the perceived likelihood of ever developing breast cancer.

Both versions of the information pack were shown to be highly acceptable to participants and to meet their needs for information and support.

7.2.4 Overall summary of main findings

The current body of work has provided an important contribution both to the psychosocial literature and the development of clinical services for women living with an increased risk of breast cancer. The work has provided evidence, in terms of objective assessment of psychological distress and the subjective views of participants, that there is a need for psychoeducational intervention among this group of women. The work has shown that such an intervention can effectively reduce

breast cancer-specific distress and improve knowledge of key issues related to breast cancer risk whilst successfully meeting the subjective needs of these women.

7.3 Limitations of the current work

Although the limitations have already been discussed for each study, this section presents the main issues that are relevant to the current work.

7.3.1 Samples

Research in women attending familial breast cancer clinics faces a series of potential sources of bias with regard to their samples of participants. Women who choose to attend genetic risk counselling are likely to be different from those who choose not to attend in terms of sociodemographic factors such as educational level and social class. Those women who then choose to attend a particular familial breast cancer clinic may receive different services from those women attending another clinic in the same country. In addition, those women who choose to participate in a specific study may be different from those to refuse to participate in terms of psychosocial factors such as levels of distress. These sorts of factors may also help to explain why some women complete their participation in a study whilst others drop out part of the way through.

As far as the current work is concerned, the participants were generally highly educated and of white ethnicity. They appeared to be representative of the women attending familial breast cancer clinics, both nationally and internationally, in terms of sociodemographic factors such as educational level and were typical of the Scottish population in terms of ethnicity. However, it was not possible to ascertain whether the participants were representative of those women who choose not to take part on other psychological factors. Non-participants may have been biased in terms of distress and coping style: highly distressed women or those with an avoidant style of coping may have chosen not to participate. Despite these potential biases, the current work obtained a range of distress levels and degrees of coping style from participants. Nevertheless, generalising the results of the current work to all women who have been living with an increased risk of breast cancer for a number of years should be carried out with caution.

7.3.2 Measures

The measures used to assess the key constructs in the current body of work were selected on the basis of being well validated. In this relatively new area of psychological research, a limited number of measures had been developed specifically for use in women with a family history of breast cancer. Where such measures did not yet exist in this area, the most appropriate measures were chosen from other areas of psychological research or ad hoc items were developed specifically for the study.

There are a number of limitations with the measures of general psychological and breast cancer-specific distress used in the current work.

Like many other self-report measures of general psychological distress, the GHQ is a screening tool to assess probable psychiatric morbidity (Goldberg & Williams, 1991). A clinical interview is needed in order to make a clinical diagnosis to confirm the presence and type of psychiatric disorder (Goldberg & Williams, 1991). The GHQ is limited in the type of disorder it may detect: it can detect transient disorders which can diminish without intervention but may not be sensitive to enduring traits such as personality disorders (Goldberg & Williams, 1991). The choice of clinical threshold used to classify “case-level” distress should be based on several factors: the best trade-off between sensitivity and specificity, the sample and whether a clinical interview will be used to make psychiatric diagnoses (Goldberg & Williams, 1991).

The effectiveness of the GHQ-28 as a screening measure for psychiatric disorder has been investigated in 158 women three months after genetic risk counselling for breast cancer (Hopwood et al., 1998). The GHQ-28 (threshold ≥ 5) was found to classify twice as many women as having a probable psychiatric illness as was confirmed by a “gold-standard” psychiatric interview. Therefore, the prevalence of probable psychiatric morbidity found by the current work is likely to be an overestimation of the true prevalence. Further longitudinal research in women who have been living with an increased risk of breast cancer for a number of years could employ clinical interviews to confirm the prevalence and type of psychiatric disorders over a period of years.

The Impact of Event Scale includes a conditional opening question that asks participants to complete the scale only if they have thought about breast cancer in the past week. In the current work, this has meant that the majority of participants have not completed this measure which has led to limitations with the interpretation of the data from the whole scale. Further investigation on the use the opt-out box is

warranted, perhaps including a comparison of results from this measure, with and without the addition of the opt-out box.

Clinical thresholds for the measures of breast cancer-specific distress used in the current work (i.e. the Impact of Event Scale, Cancer Worry Scale) have not yet been derived. Therefore, it is difficult to confirm that the statistically significant findings on these measures in the current work were also of clinical significance. The development of clinical thresholds for measures of breast cancer-specific distress warrants further research.

There are limitations of using self-report measures of distress. Myers (2000) reviews these limitations with regard to individuals with a repressive coping style, estimated to form 10-20% of the general population. These individuals typically produce low scores on trait anxiety but exhibit “high levels of physiological activity”. This is because they “disassociate their somatic reactions from their perceptions of stress”. This can affect the results of questionnaire studies measuring psychological or physical outcomes. Research has linked a repressive coping style to a number of poor physical health outcomes e.g. cancer and cardiovascular disease. There is evidence that self-report questionnaires and face-to-face interviews will produce different results in individuals with a repressive coping style. It is suggested that the use of multiple methodologies may be the best way to overcome this problem. Qualitative methodologies such as semi-structured interviews where the data could be coded by several independent raters could be used in conjunction with measures to identify repressive coping style.

7.3.3 Theoretical models

Like a substantial amount of the research in women with a family history of breast cancer, the current work was directed from a clinical rather than a theoretical perspective. At the time of starting the current work an appropriate theoretical model that included the constructs of interest was not identified among the psychological literature. Since that time, one particular model of stress and coping has been published (i.e. Folkman & Greer, 2000) which may be relevant to the current work. Support for this theoretical model from the results of the current work and suggestions for further research to enhance our theoretical understanding of living with an increased risk of breast cancer are discussed in Section 7.5, page 201.

7.4 Clinical implications

Despite the limitations, there are still a number of important clinical implications of the main findings of the current work regarding general psychological distress, breast cancer-specific distress and psychoeducational intervention.

Probable psychiatric morbidity was indicated in about one third of participants which is similar to the prevalence in the general population. Given these findings it could therefore be argued that it is not the responsibility of the familial breast cancer clinic to screen for general psychological distress which would also require diagnosis by clinical interview before referral to appropriate treatment. Indeed performing such a screening assessment during a routine breast cancer screening appointment is likely to produce biased results, as the measure may be sensitive to transient increases in distress which are likely to accompany attendance at the clinic.

Perhaps of greater clinical importance was the finding of a widespread prevalence of breast cancer-specific distress, particularly in terms of worry about breast cancer risk. This emphasises the importance of identifying and providing support to minimise this type of distress, which may be more clearly seen as the responsibility of the familial breast cancer clinic. Firstly, it would be important to determine if any breast cancer-specific distress was preventable. The findings of the current work indicate that certain factors may be protective (e.g. greater knowledge about issues related to familial breast cancer, being married or living with a partner, greater satisfaction with social supports) whilst others may increase vulnerability to distress (e.g. greater perceived risk of developing breast cancer, higher Monitoring/Emotional Uncertainty coping style, having a psychiatric history, lower educational level). The confirmation of the role of some of these factors that are amenable to intervention could have the potential to minimise the negative psychosocial impact of living with an increased risk of breast cancer. Secondly, it seems likely that a certain amount of breast cancer-specific distress is inevitable for women in this situation. Therefore, it would be important to determine the most effective ways of minimising distress in these women as a whole and to identify those women who may still suffer from high levels of distress which may benefit from treatment on a more individual basis.

The current work has shown that a psychoeducational intervention consisting of written information on psychosocial and scientific topics of information related to familial risk of breast cancer was shown to effectively reduce cancer worry and

improve scientific knowledge relevant to living with an increased risk of breast cancer. The intervention was generally shown to be highly acceptable to these women and to meet their needs for information and support. This type of intervention could be incorporated into routine clinical practice, thus providing these women with the type of ongoing psychosocial support that many familial breast cancer clinics are currently lacking. Further investigation is warranted to determine how the information pack could form part of the existing clinical service and what would be required to maintain it e.g. regular updating of information. However, an economic evaluation of the intervention would be required to determine whether it would be a cost-effective addition to the clinical service. This type of intervention could be compared to an alternative such as web pages, group meetings or telephone discussion groups to determine the most cost-effective and clinically effective service.

The psychoeducational intervention, if appropriately modified, also has potential value in other groups of women with a family history of breast cancer (e.g. women estimated to be at low risk of breast cancer who are not enrolled in a familial breast cancer clinic or who have been discharged from a familial breast cancer clinic after several years attendance). This type of psychoeducational intervention also has the possibility of being valuable in populations at increased risk of other forms of cancer such as ovarian cancer.

7.5 Theoretical perspective

There is a clear need to develop a better theoretical understanding of the within- and between-individual variation in levels of psychological distress in women living with an increased risk of breast cancer.

One model which may be particularly useful in providing a theoretical framework for the results of the current work is the model of stress and coping proposed by Folkman & Greer (2000) (Figure 7.1). This recently developed model was derived from a cognitive model developed by Lazarus & Folkman (1984) in an attempt to explain the role of psychological well-being during serious illness. The more recent version of the model makes substantial additions to the original model, some of which represent key constructs of the current work (i.e. person characteristics represent sociodemographic factors, objective risk and coping style).

Two key processes are included in the model: appraisal and coping. Appraisal consists of primary appraisal, which is an evaluation of the personal importance of a

particular situation and secondary appraisal, the evaluation of resources to cope with that situation. Appraisal is postulated to influence the type of coping that follows. The thoughts and behaviour that an individual uses to cope with a particular situation are classified by the model as “problem-focused” (which targets the source of distress), “emotion-focused” (which manages distress) and “meaning-based coping” (which sustains “positive well-being”). Both the outcome of the situation in terms of distress and positive emotion and the appraisal of the situation are influenced by these coping processes. In addition, stable or variable characteristics of an individual or their environment can influence the appraisal and coping processes. Therefore, this model is dynamic as the different aspects it includes are all interdependent.

Although the quantitative studies of the current work did not investigate coping as a process (situation-specific coping) or positive psychological well-being, the findings nevertheless provide some support for sections of the stress and coping model. Firstly, certain characteristics of an individual both stable (e.g. coping style) and variable (e.g. perceived likelihood of developing breast cancer) were shown to impact on the relationship between living with an increased risk of breast cancer and psychological distress. Secondly, primary appraisal in terms of perceived risk of developing breast cancer and secondary appraisal in terms of perceived satisfaction with social supports were also found to affect this relationship. Thirdly, when external resources to cope with the situation were enhanced (i.e. when the women received a psychoeducational intervention), psychological distress in terms of worry about cancer was reduced. There was also evidence that knowledge of scientific issues related to familial risk of breast cancer, which could be an internal coping resource, was enhanced due to the presence of the psychoeducational intervention.

Therefore, the findings of the current work provide considerable support for value of this model in enhancing our theoretical understanding of living with an increased risk of breast cancer. However, it could be argued that this model does not adequately account for the findings of the current work regarding the impact of breast cancer cues on psychological distress. Future research in women living with an increased risk of breast cancer could attempt to clarify the effect of different types of breast cue on distress to enable this model to be further developed to provide a better theoretical explanation of fluctuations in distress over time.

Two additional theoretical models (i.e. the monitoring process model and the cognitive-behavioural model of health anxiety) have been identified from the psychological literature. Although these models may also be of value when considering the findings of the current work, this may arguably be to a lesser degree than Folkman & Greer’s (2000) model of stress and coping.

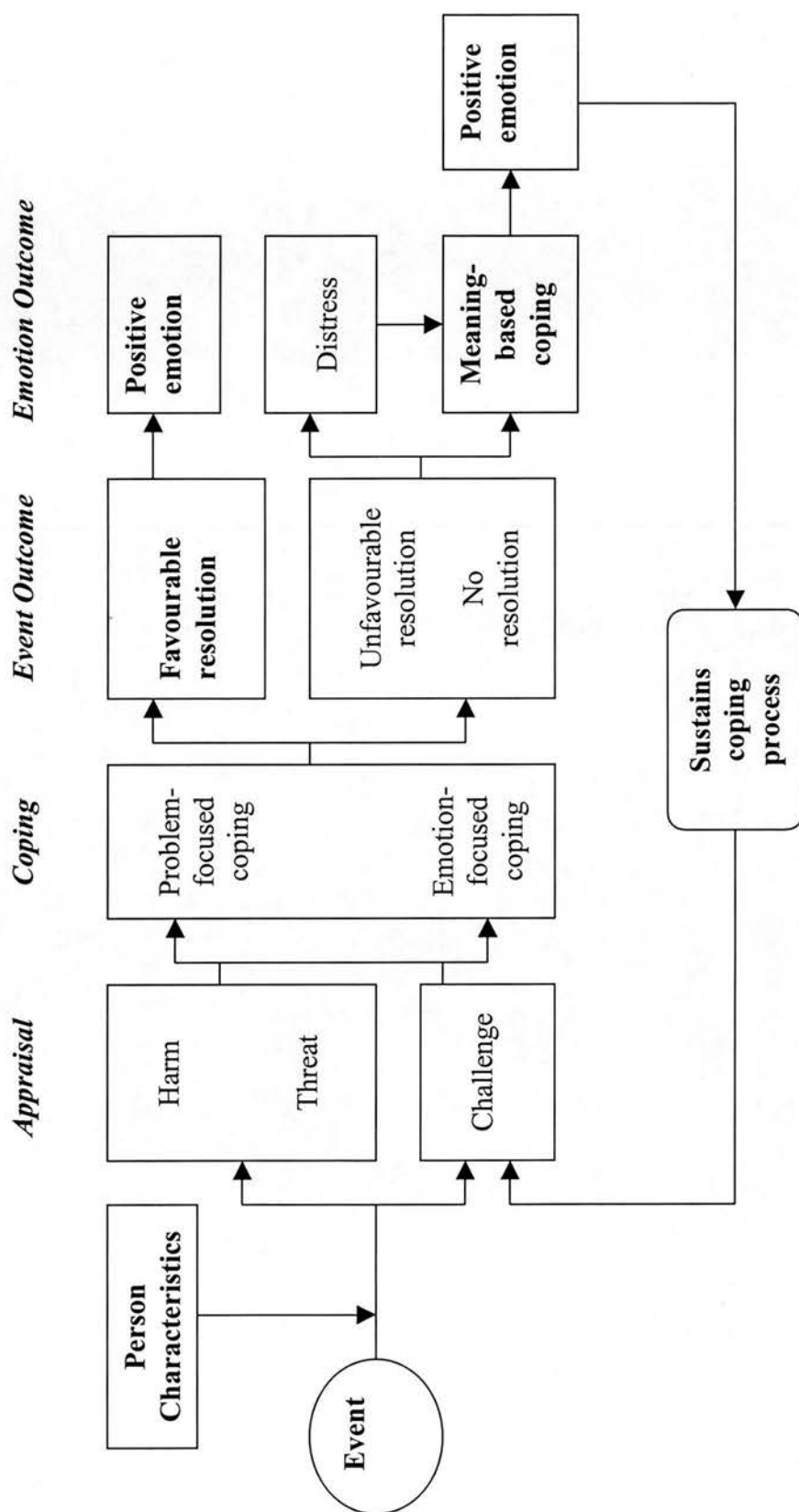


Figure 7.1: Theoretical model of stress and coping (Folkman & Greer, 2000)

The monitoring process model (MPM) focuses on how individuals with a high monitoring coping style differ from those with a low monitoring coping style in the way that they cope with a severe long-term health threat (Miller et al., 1995) (Figure 7.2).

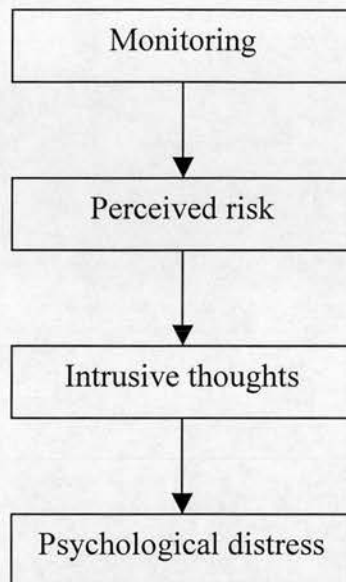


Figure 7.2: The monitoring process model (Miller et al., 1995)

According to this model, individuals with a high monitoring coping style tend to scan and attend to cues related to the specific threat. These individuals are likely to perceive ambiguous or non-threatening information about the specific threat as extremely threatening which results in heightened perceived personal risk. This in turn produces high levels of intrusive thoughts about the threat. The heightened perceived risk together with the high levels of intrusive thoughts are likely to cause psychological distress for those individuals with a high monitoring coping style. Evidence to support the MPM has been obtained in several different samples including women with a family history of ovarian cancer (Schwartz et al., 1995).

The findings of the current work provide limited support for the MPM. Some relationships proposed by the model were not tested by the current work and of the relationships that were tested, support for the model was not always obtained. A high monitoring coping style and greater perceived likelihood of developing breast cancer were both shown to be predictive of breast cancer-specific distress in terms of worry about breast cancer risk-related issues, but not general psychological distress. In addition, there was no evidence of a relationship between monitoring and intrusive

thoughts about breast cancer. Differences in the samples used in the current work and those used in the development and support of the MPM (e.g. in terms of their specific health threat, nationality) may help to account for the lack of support provided by the current work for the MPM.

A cognitive-behavioural model of health anxiety was originally developed to explain the development and maintenance of hypochondriasis (Warwick & Salkovskis, 1990) (Figure 7.3). It has since been applied to less severe or transient forms of health anxiety in the general population (e.g. Hadjistavropoulos et al., 1998). The model proposes that both previous experience and information (e.g. from the media) can lead to the formation of dysfunctional cognitions (e.g. every physical symptom is a sign of serious illness). These dysfunctional cognitions can be prompted by “critical incidents” (e.g. a physical symptom) which results in health anxiety. The maintenance and exacerbation of this anxiety is caused by cognitive processes (e.g. attentional bias towards illness-related information, cognitive bias towards perceiving all information as highly threatening) and behavioural processes (e.g. avoidance, excessive reassurance-seeking). The anxiety itself can cause physiological symptoms which may act as “critical incidents”, prompting dysfunctional cognitions and further increasing health anxiety. Croyle (1992) suggests that the ambiguous nature of a health threat is likely to allow cognitive biases to be developed.

As this model has previously been used successfully to explain a wider spectrum of levels of health anxiety than hypochondriasis alone, it may be relevant to help understand the high levels of breast cancer-specific distress that were experienced by some participants. However, it should be noted that the current work did not quantitatively assess health anxiety, although the measures of breast cancer-specific distress used in the current work could be regarded as related to health anxiety.

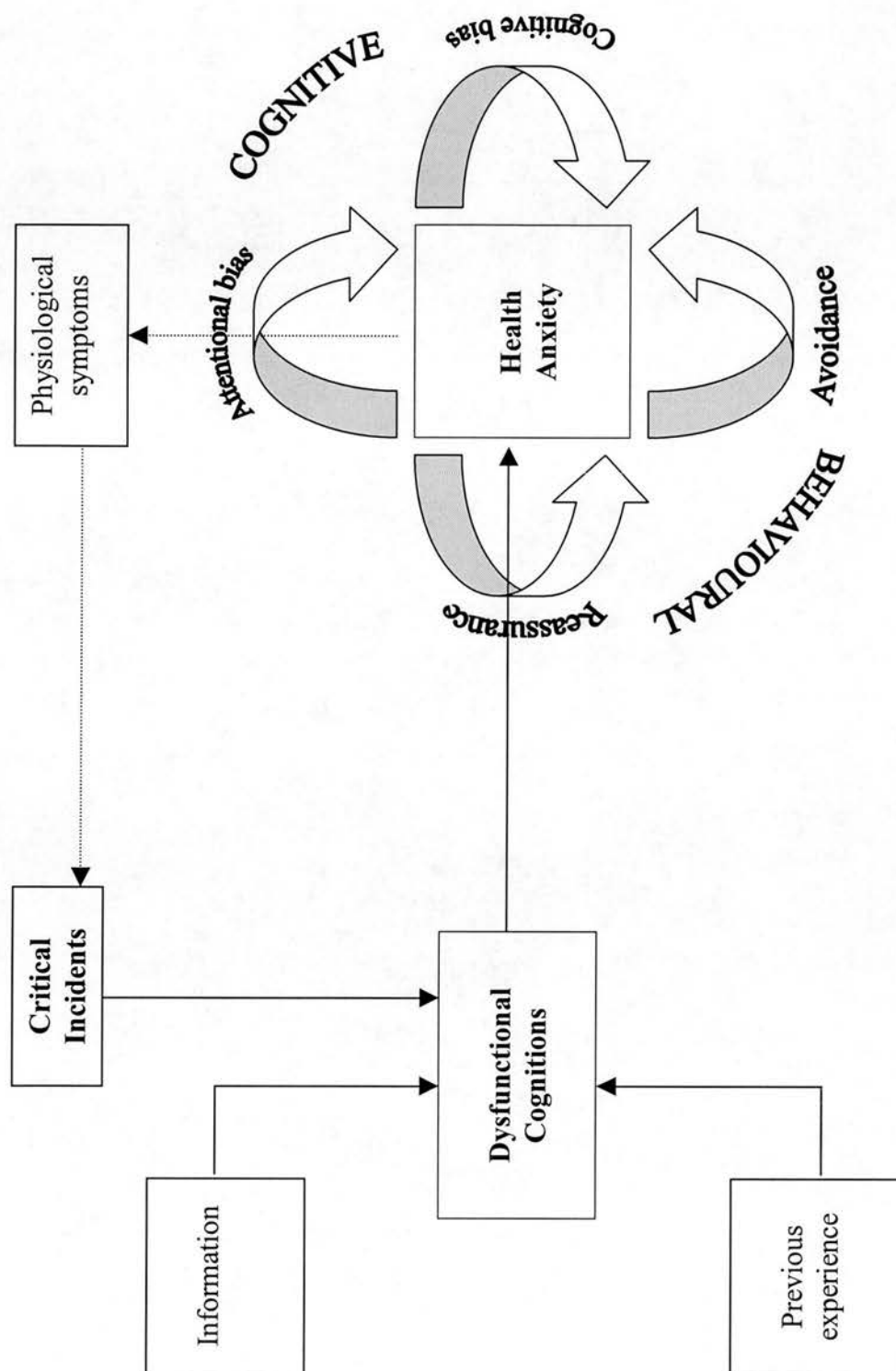


Figure 7.3: Cognitive-behavioural model of health anxiety (adapted from Warwick & Salkovskis, 1990)

There is evidence from the qualitative findings of the telephone focus group study that this model may provide a useful theoretical framework to help understand some of the participants' experiences. For example, one participant described a relationship between the constructs included in the model (i.e. previous experience, information, dysfunctional cognitions, critical incidents and health anxiety):

"...there's quite a history of cancer in my family anyway and I would describe myself as being a bit of cancer phobe.... My reaction tends to be if somebody's ill, my first reaction is, 'Oh God it's cancer' or if there's something wrong with me or people close to me like my partner or my son, my first reaction is, 'I hope it's not cancer'". For this woman, information about breast cancer risk together with personal experience of cancer in the family resulted in a belief that all physical symptoms indicate cancer. This belief, triggered by illness in the family, led to a phobia about cancer.

This model offers the means of both understanding and treating health anxiety which may manifest itself in different forms (e.g. excessive levels of worry, breast self-examination and reassurance seeking) in women living with an increased risk of breast cancer.

Consideration of the value of these three theoretical models in providing a framework for our understanding of the psychosocial effects of living with an increased risk of breast cancer, points to the potential use of a two-tier theoretical model. The stress and coping model developed by Folkman & Greer (2000) seems to be particularly valuable in explaining the experience of the majority of women and indicating factors that may be amenable to intervention. In contrast, the cognitive-behavioural model of health anxiety (Warwick & Salkovskis, 1990) is useful in explaining the experience of and suggesting effective treatment for the minority of women who are highly anxious about their health. It would be pertinent for these two models to form a basis of future theoretically-driven research in this group of women. This research could have a view to developing a two-tier theoretical model that would help to explain fluctuations in breast cancer-specific distress experienced by the majority of women, whilst also providing a framework for the explanation and treatment of chronic high levels of anxiety about breast cancer.

7.6 Further research

Although suggestions for future research have been already been given for each study, this section summarises some of the main areas worthy of further

research in women living with an increased risk of breast cancer. The findings of the current work and evidence from the recent psychological literature have identified main areas: coping process, psychological well-being, physical health and clinical services.

7.6.1 Coping process

As indicated by the qualitative results of the current work together with several theoretical models, further research could focus on the processes whereby women cope with living with an increased risk of breast cancer. Unlike coping style, which regards coping as a stable trait, coping process highlights within-individual differences over time, between-individual variations and the influence of context (Lazarus, 1993). Coping process is described as: “ongoing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus, 1993). Coping processes are not inherently “good or bad”, although some may be effective more frequently than others (Lazarus, 1993). The effectiveness of coping processes in adapting to a specific situation varies between individuals, situations, time-frames and outcomes assessed (Lazarus, 1993).

It would be useful to investigate the coping processes used in the specific context of living with an increased risk of breast cancer and in the common type of situations that entails (e.g. coping between clinic appointments). This would enable strategies that are generally adaptive to be identified and promoted through appropriate interventions.

A limited number of studies to date have investigated coping processes in women with a family history of breast cancer. Gilbar (1998) found that the coping processes adopted (e.g. denial, information-seeking) when waiting for a breast screening appointment were similar in women with and without a family history of breast cancer. Audrain et al. (1999) evaluated a coping skills intervention including problem-solving training which aimed to “enhance adaptive coping” concerning the stressful experience of having a family history of breast cancer. The intervention was found to be effective in improving adherence to breast self-examination and was shown to be most beneficial in women with high levels of cancer-specific distress.

7.6.2 Psychological well-being

Recent psychological literature (i.e. Folkman & Greer, 2000) has suggested that when conducting research on the psychological stress of confronting a serious health threat, it is just as important to investigate positive outcomes of the situation (i.e. psychological well-being) as negative outcomes (i.e. psychological distress), which have traditionally been the focus of much research. Psychological well-being generally refers to “positive affective and positive cognitive psychological states” (Folkman & Greer, 2000). The limited research that has investigated psychological well-being has provided evidence that these positive emotions and cognitions can be experienced even in extremely stressful situations (Folkman & Greer, 2000). Three types of coping process have been proposed to enable individuals to “experience positive emotions during long periods of severe stress” (Folkman & Moskowitz, 2000): positive reappraisal, problem-focused coping and creating positive events (Folkman, 1997).

Future research in women living with an increased risk of breast cancer could investigate various aspects of psychological well-being such as the role of positive emotions in adapting to a long-term stressor as well as the coping processes that sustain psychological well-being. The findings could then provide the potential for developing and evaluating a psychological intervention to promote factors that are found to be important in effective adaptation.

7.6.3 Physical health outcomes

There is a growing body of controversial research investigating the links between psychological distress and physical health. In a recent review of the literature on this relationship, there was evidence of a link between psychological distress in terms of anxiety and depression and the onset and progression of various diseases such as cancer (Kiecolt-Glaser et al., 2002). There are a number of direct (e.g. immune function) and indirect (e.g. health behaviours) ways in which distress affects physical health (Kiecolt-Glaser et al., 2002). In addition, several factors (e.g. sociodemographic variables, personality traits, coping style, social support) may be protective of or increase vulnerability to health outcomes. A review of psychoneuroimmunology research provides evidence of an association between psychological distress and immune suppression, particularly in terms of natural killer cell activity (Kiecolt-Glaser & Glaser, 1999). The authors suggest that: “stress can alter a potentially important defence against malignant disease”.

Of the limited number of studies to date investigating immune function in individuals with a family history of cancer, Bovbjerg & Valdimarsdottir (1993) found evidence of a psychoneuroimmunological relationship. The level of immune functioning in 11 healthy women with at least one first-degree relative with cancer was lower than for 32 healthy women without a family history of cancer in a first-degree relative. Women from both groups with greater levels of distress showed lower levels of immune functioning, which continued to be lower even when the effect of distress was removed statistically. Given the small sample size in this study, the results should be interpreted with caution.

Despite evidence of links between psychological distress and immune function and immune function and physical illness, evidence of a causal role between distress and cancer has yet to be proven. Although this controversial research is very much in its infancy, it does have the potential to be extremely relevant to women at increased risk of breast cancer. Further research in this population is warranted to determine whether chronic distress in women living with an increased risk of breast cancer further elevates their susceptibility to breast cancer. Longitudinal research in women at increased risk of breast cancer could monitor distress levels and record breast cancer morbidity and mortality and investigate the role of factors such as immune functioning over a period of years.

Research has already shown that some psychological interventions can impact on immune functioning both in healthy individuals and cancer patients. Miller & Cohen (2001) conducted a meta-analytic review of 59 psychological interventions that had assessed immune outcomes. There was evidence that psychological interventions, particularly involving hypnosis or conditioning, could alter particular aspects of immune function. For example, Fawzy et al. (1990a & b) found that a six-week multifaceted psychiatric intervention in skin cancer patients resulted in decreased psychological distress, enhanced adaptive coping processes and improved aspects of immune function. All of these benefits were sustained up to six months following the intervention. However, these findings were not consistent across all of the studies included in the meta-analysis, which the authors suggest may be attributable to methodological limitations of the studies (Miller & Cohen, 2001). They suggest that future trials are needed to clarify the relationship between psychological intervention and immune function.

It is therefore possible that some form of psychosocial intervention could benefit women living with an increased risk of breast cancer in a number of ways including enhanced immune function. Future research is warranted to develop and evaluate the impact of such an intervention that may have the potential to provide

these women with long-term physiological benefits that could ultimately affect their risk of developing breast cancer.

7.6.4 Clinical services

Recent changes in the clinical services that are offered to some women at increased risk of breast cancer have raised important questions which warrant further psychological research. Some women who have been attending a familial breast cancer clinic for a number of years are being discharged. This is because advancing knowledge of breast cancer genetics has shown that these women are at low risk of developing breast cancer and due to limited resources within the National Health Service, it has been necessary to prioritise the clinical services for women with a family history of breast cancer who are most at risk of developing the disease. However, this has important psychological implications for these women who have been living with an increased risk of breast cancer for several years before they have been informed that they are no longer at sufficiently increased risk to warrant routine breast cancer screening out with the National Breast Cancer Screening Programme. It would seem highly appropriate for future psychological research to monitor these women after they had been discharged from the familial breast cancer clinic. This research could provide the information necessary to prevent and treat any negative psychological effects that these women could experience as a result of changes in clinical guidelines and services.

7.7 Conclusion

The series of three studies presented in this thesis have made an important contribution to our understanding of the psychosocial effects of living with an increased risk of breast cancer. The findings have made a substantial addition to the previously limited psychological literature on this large and growing group of women. They have provided evidence of the inadequacy of the existing clinical services in meeting the psychosocial needs of these women and have shown that these needs can effectively be met through the introduction of a brief psychoeducational written intervention. The results of the current work have helped to inform both future psychological research and the development of clinical services for women living with an increased risk of breast cancer.

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Appendices

Appendix I:

Published paper: Appleton S, Fry A, Rees G, Rush R and Cull A (2000).
Psychosocial effects of living with an increased risk of breast cancer: an exploratory study using telephone focus groups. *Psycho-Oncology* 9: 511-521.

Appendix II:

Copies of questionnaires and other relevant documents.

Appendix III:

Psychoeducational written intervention.

PSYCHOSOCIAL EFFECTS OF LIVING WITH AN INCREASED RISK OF BREAST CANCER: AN EXPLORATORY STUDY USING TELEPHONE FOCUS GROUPS

SALLY APPLETON*, ALISON FRY, GWYNETH REES, ROBERT RUSH and ANN CULL

Psychosocial Research Group, Imperial Cancer Research Fund, Medical Oncology Unit, Western General Hospital, Edinburgh, UK

SUMMARY

Research to date has mainly focused on the *short-term* psychological impact of genetic risk counselling for breast cancer. This study aimed to explore the *long-term* consequences for women of being informed about an increased risk of breast cancer in terms of: the effect on their everyday lives, their coping strategies and their unmet needs in terms of the current service. The participants were 25 women with a family history of breast cancer who had received genetic risk counselling and had consequently been receiving clinical surveillance for at least 2 years. They took part in one of seven telephone focus groups and subsequently completed a feedback questionnaire. Transcripts of the focus groups were qualitatively analysed by three independent researchers with inter-rater agreement between pairs of raters ranging from Kappa = 0.61–0.79. Six key issues emerged from the data, which provide an important insight into the long-term consequences of living with an increased risk of breast cancer concerning: (1) psychological adaptation, (2) behavioural adaptation, (3) family issues, (4) clinical surveillance, (5) provision of information, and (6) peer support. These findings, together with the quantitative results of the feedback questionnaire, have clinical implications that require further investigation in larger scale quantitative research. Copyright © 2000 John Wiley & Sons, Ltd.

INTRODUCTION

A family history of breast cancer is an important known factor that puts women at increased risk of the disease (Claus *et al.*, 1990; Slaterry and Kerber, 1993). Women who have a first-degree relative affected by breast cancer are two to three times more likely to develop breast cancer than women without any family history of the disease (Slaterry and Kerber, 1993). As public awareness of family history as a risk factor for breast cancer has grown in recent years, increasing numbers of women have sought information about their personal cancer risk.

A growing number of clinics have been established to offer genetic risk counselling and advice about risk management strategies to women with

a family history of breast cancer. For the majority (i.e. those who are not eligible for genetic testing), their risk of developing breast cancer will be derived from their own age and the characteristics of their family history using epidemiological data and mathematical models (e.g. Claus *et al.*, 1990). However, for the individual woman there are large margins of uncertainty surrounding the risk estimate. The majority of women who are found to be at least at a moderately increased risk are usually offered clinical surveillance in the form of mammography and clinical breast examination. The age at which surveillance begins for a woman at increased risk and the recommended frequency of mammography may vary according to the individual's age and history (e.g. the age at which their youngest affected relative was diagnosed). In the UK, all women are eligible to join the National Breast Cancer Screening Programme from the age of 50. (The American Cancer Society, 2000, recommends all women aged 40 and over have an annual mammogram and clinical breast examination.) The efficacy of screening women

* Correspondence to: Department of Clinical Psychology, Outpatient Building, Western General Hospital, Crewe Road, Edinburgh EH4 2XU, UK. Tel.: +44 131 5371838; fax: +44 131 3436869; e-mail: s.appleton@icrf.icnet.uk

with a family history of breast cancer aged less than 50 years remains controversial. Data are now emerging to support the value of regular mammography and clinical breast examination in this population (i.e. Kollias *et al.*, 1998; Lalloo *et al.*, 1998) but the sample sizes to date have been too small to provide unequivocal evidence. Given the uncertainty of the risk estimate, the doubts about the value of screening and the prospect of years of surveillance, there is clearly a potential for psychological morbidity in this population. In our setting of a Familial Breast Cancer Clinic in South-East Scotland, there is no formal provision of psychosocial support specifically for these women. Therefore, the only form of support routinely available is limited to follow-up clinic appointments that focus on breast cancer screening.

The majority of research to date on the psychological impact of informing women of an increased risk of breast cancer has assessed women up to 1 year after genetic risk counselling. Such *short-term* effects have been investigated in terms of psychological distress, risk perception and adherence to breast self-examination (BSE) (e.g. Gagnon *et al.*, 1996; Lerman *et al.*, 1996; Hopwood *et al.*, 1998; Cull *et al.*, 1999; Watson *et al.*, 1999). Although some studies have found that levels of general psychological morbidity in women who have received genetic risk counselling are not significantly different from other general population samples (e.g. Cull *et al.*, 1999), there is evidence that these women experience high levels of breast cancer-specific distress (e.g. Watson *et al.*, 1999). Of the very limited research to date into the *long-term* psychosocial consequences of informing these women about their increased risk, high levels of breast cancer-specific distress have been found in women who had received genetic risk counselling up to 25 months previously (Lloyd *et al.*, 1996). There could be a number of important implications both for individuals and clinical services if chronic psychological distress was found to be prevalent in women who have been living with an increased risk of breast cancer for a number of years.

In terms of implications for the individual, research in women with a family history of breast cancer has indicated that high levels of anxiety and distress are associated with non-adherence to BSE (e.g. Kash *et al.*, 1992), clinical breast examination (e.g. Kash *et al.*, 1992) and mammography (e.g. Lerman *et al.*, 1993). If surveillance is proven to be effective in this population, chronic

distress may elevate the risk of death from breast cancer for women already estimated to be at increased risk of the disease.

As the number of referrals to familial breast cancer clinics grows, resources are stretched and clinical contact for women already living with an increased risk may be progressively limited. Pressure on these services would be further increased if chronically distressed individuals required more frequent or longer appointments (or if some of these women missed their appointments altogether).

In addition, there may be important implications for future generations within the same family. Women who are living with an increased risk of breast cancer and who are chronically distressed may represent maladaptive role models for the next generation who are also likely to face living with this constant threat.

It was clear that there is a need to investigate how the expanding numbers of women on regular surveillance over a period of years live with the knowledge of their increased risk. The aim of this study is to explore the long-term consequences of being informed about an increased risk of breast cancer in terms of: the effect on everyday life, the coping strategies used and unmet needs in terms of the current service.

In order to conduct this exploratory research, we have used a novel methodology of telephone focus groups. Focus groups are an ideal means of undertaking exploratory research (Vaughn *et al.*, 1996) as information on a range of experiences can be collected simultaneously (Seals *et al.*, 1995). However, adopting this methodology to inform the study aims posed practical problems of cost and inconvenience to women living within a large radius. Therefore, the focus groups were conducted via a telephone conferencing system, operated by Community Network, a centre for voluntary sector telephone conferencing.

METHODS

Sample

The sample was derived from a database of women at least at moderately increased risk of breast cancer who had been attending the South-East Scotland Familial Breast Cancer Clinic for no less than 2 years. Women were excluded if they

had been diagnosed with cancer, had undergone prophylactic surgery or were currently participating in any other psychosocial research or clinical trial.

An initial sample of 50 women was identified by selecting every third woman from a list of 155 potential participants. When the participation rate was found to be low after 2 weeks (44%), a further 20 women were randomly selected from the remaining 105 potential participants.

Instruments: Moderator Guide

Prior to this study, 12 pilot interviews were conducted with women at increased risk of breast cancer who were attending the South-East Scotland Familial Breast Cancer Clinic for routine follow-up. Data from these interviews were used to develop standard stimulus questions and probes which formed the main section of a semi-structured moderator guide. This consisted of:

- a standard introduction to:
 - welcome participants.
 - set ground rules (e.g. participants identify themselves before speaking by their first name only).
 - allow participants to introduce themselves.
- standard stimulus questions and probes to ensure that each group discussed the following three main topics:
 - *effects* of living at an increased risk on everyday life.
 - *coping* with an increased risk.
 - unmet needs in terms of the current *service*.
- a standard conclusion to:
 - thank participants.
 - allow participants to say goodbye.

Instruments: Feedback Questionnaire

A short feedback questionnaire was developed to clarify some of the opinions that were raised in the telephone focus groups, to provide feedback on participation and additional information on participants. The questionnaire consisted of four main sections:

1. Living with an increased risk of breast cancer: eight items concerning effects on everyday life and difficulties coping (e.g. 'Have you found it difficult to cope with knowing that there is an

increased risk of breast cancer in your family?'—response on a 4-point Likert scale from *not at all* to *very much*).

2. Service issues: ten items to clarify unmet needs and preferences for the method of delivering these services (e.g. 'Would you like to be provided with the opportunity to meet up with other women in the same situation?'—response as a *yes/no* choice).
3. Participating in a telephone focus group: seven items to provide feedback on the acceptability of the telephone focus group methodology (e.g. 'How would you rate your general experience of taking part in the telephone discussion group?'—response on a 4-point Likert scale from *poor* to *excellent*).
4. Genetic testing: four items to identify if any participants had been through the genetic testing process (e.g. 'Has a faulty breast cancer gene been identified in your family?'—response as *yes/no* choice).

Procedure

Each woman was sent information about the study and invited to participate. Those who consented to take part were allocated to a telephone focus group at a time to suit their convenience. A short telephone call to the women several days prior to their scheduled group reconfirmed their participation and allowed the moderator to explain how the group would be conducted.

Each group had the same moderator (SA) who had been trained to facilitate telephone conference calls. The participants were telephoned by the Community Network operator to connect them to the conference call (i.e. the participants were not charged for the call). The telephone focus groups were conducted following published guidelines for focus groups (Tobin, 1996; Vaughn *et al.*, 1996; Greenbaum, 1998), which were modified for use with the telephone conferencing system. All groups lasted for no longer than 1 hour and all were audiotaped by Community Network.

Immediately after each group, the moderator made a summary of the discussion. These summaries were compared with the final outcome of the qualitative analysis as an indication of the reliability of these results (Table 1; Stage 2, Step 4).

Table 1. Qualitative analysis of telephone focus group data

Stage 1.

For each of the three research areas separately (i.e. Effect, Coping, Services):

1. Informative quotes identified (SA, AF, GR)^a.
2. Consensus achieved on a final list of quotes (SA, AF, GR).
3. Themes developed from the quotes (SA).
4. Reliability of themes assessed. Quotes independently assigned to themes (AF, GR). Inter-rater reliability between pairs of the three raters calculated.
5. Discrepancies negotiated to achieve consensus on a final set of themes with supporting quotes (SA, AF, GR).

Stage 2.

Completed by SA only:

1. Themes and supporting quotes from each of the three research areas collapsed to form 1 dataset of 44 themes and 756 quotes.
2. Extraction of 29 themes supported by quotes from at least 3/7 transcripts.
3. Related themes grouped to form six key issues.
4. Reliability of six key issues assessed by comparing to the moderator's summaries of the telephone focus groups.

^a Initials refer to the named authors.

The participants were invited to give feedback on their experience of participating several days after their group through a short postal questionnaire.

Analysis

The audiotapes of the telephone focus groups were transcribed verbatim and analysed independently by three researchers using a modified version of published guidelines for analysing focus group data (Vaughn *et al.*, 1996). The process by which quotes, themes and key issues were identified in two main stages is explained in Table 1.

On completion of the qualitative analysis, the feedback questionnaire was quantitatively analysed in terms of descriptive statistics.

RESULTS

Participants

Of the 70 women invited to participate, 33 (47%) responded, of whom 25 (36%) participated in the study (five women who responded were unable to take part over the scheduled time period and three were unwilling to participate for personal reasons, e.g. mother had recently received a diagnosis of recurrent breast cancer). The 37 women (53%) who did not respond to the initial

invitation were not contacted for a second time. Seven telephone focus groups were conducted of which five groups had four participants and the remaining two groups comprised three and two participants, respectively.

There were no significant differences between the participants and non-participants in terms of their age, marital status, number of children, number of daughters, duration of clinic attendance and counselled risk of developing breast cancer.

Participants ranged in age from 27 to 51 years (mean 41.3 years, S.D. 5.9 years). The majority were married or cohabiting (80%), had children (76%) and of those that had children, 63% had at least one daughter. They had been attending the clinic for between 2.5 and 6.5 years (mean 5.2 years, S.D. 1.2 years). Their counselled risk of developing breast cancer in their lifetime ranged from 20 to 40% (mean 27.1%, S.D. 7.1%).

Key issues

The thematic structure of the six key issues is shown in Table 2. Inter-rater agreement between pairs of the three raters to assess the reliability of the themes was good (Kappa = 0.61–0.79) according to published guidelines (i.e. Altman, 1997). The six key issues reflected the main issues included in the moderator's summaries of the telephone focus groups.

Table 2. Structure of the key issues

Key issue	Theme	Number of supporting quotes	Number of transcripts containing the theme (max 7)
Psychological adaption	• Chronic emotions & cognitions	75	7
	• Acute emotions & cognitions	31	7
	• Sensitivity to breast cancer cues	27	7
	• Time & age	23	6
	• Focusing on the present	16	5
	• Avoidance	18	6
	• Positive thinking	7	5
	• Decisions & plans	22	6
Behavioural adaption	• Reassessment of life & priorities	24	7
	• General health behaviours	25	7
	• Control	6	4
Family issues	• BSE	12	6
	• Family	52	7
	• Emotional support	14	6
	• Breast cancer survivors	13	4
Clinical surveillance	• Children	35	7
	• Frequency of clinic appointments	12	3
	• Duration of clinic appointments	7	3
	• Continuous support	5	3
	• Clinical services	21	6
	• Specialist care	30	7
Provision of information	• Reassurance & security	36	7
	• Knowledge	22	7
	• Getting a balance	6	3
	• Type of information	37	7
	• Method of information presentation	28	6
	• Family involvement	14	6
Peer support	• Immediate telephone contact	17	6
	• Support from other women in the same situation	17	5

Psychological adaptation

A common way of adjusting to knowing about an increased risk in the long-term was described as 'taking one day at a time'. Women discussing their *chronic emotions & cognitions* commonly felt there was nothing to be gained from considering uncertain future scenarios. Other women described varying levels of breast cancer worry from mild or subconscious to severe worry and intrusive thoughts.

I think maybe the hardest thing I've had to do is to accept that this (breast cancer) will be an ongoing fear, there will never come a time in my life when I will know, at least with current medicine as it is,

there probably will never come a time when I will think, well this is something I won't get.

Acute emotional & cognitive responses such as anxiety, depression, shock, surprise and feelings of neglect were described as being triggered by risk-related events, such as being initially informed about their increased risk (by a health professional), receiving an appointment letter, waiting for an overdue appointment, having a mammography or biopsy and receiving the results (even if they showed no signs of breast cancer).

Some women described a heightened *sensitivity to breast cancer cues*, such as changes in their breasts, media reports about breast cancer and

illness in the family. This either prompted increased vigilance through BSE, greater interest in media reports, increased anxiety or the avoidance of these cues.

I would describe myself as being a bit of cancer phobe... My reaction tends to be if somebody's ill, my first reaction is, 'Oh God it's cancer' or if there's something wrong with me or people close to me like my partner or my son, my first reaction is, 'I hope it's not cancer'.

Emotional & cognitive fluctuations over time were described, particularly in relation to the annual screening cycle.

... it's when the time of the year comes, May-June period, that's when it actually, you're facing it front on and that for me is the hardest thing to cope with, waiting for the mammogram, waiting for the results and wondering if it's positive, how you're going to cope with it and then you get the letter through to say it's negative and then you sigh another sigh of relief for another year.

Breast cancer awareness, fear or worry commonly increased as the women approached the age at which an affected relative had been diagnosed with breast cancer: an effect described as 'a psychological cut-off date', like 'a time bomb' or 'a big shadow'. Conversely, once this age had been passed, any increase in anxiety levels gradually subsided.

The women described a variety of cognitive strategies for coping with the knowledge of their increased risk, such as *focusing on the present*, *avoiding* potentially worrying breast cancer cues and *thinking positively* about the situation by adopting an optimistic attitude about the future.

Although knowing about their increased risk had generally not affected the women's *decision-making* or *planning* for the future, anxiety was expressed about having to make important choices in the future regarding genetic testing or preventative surgery.

Knowing about their increased risk of breast cancer had prompted several women to *reassess their lives & priorities* in positive ways, such as living life to the full and prioritising their health.

Behavioural adaptation

Although some women were already maintaining a healthy lifestyle, for many knowing about their increased risk had prompted them to adopt

new *general health behaviours*, such as a healthy diet, exercise, stopping smoking, use of natural remedies and stress management.

The women described how these behaviours helped them to gain some *control* over their increased risk

... all these things help you to feel you are in control of the situation rather than the situation is in control of your life so I think it is very important to do things, positive things, to make you feel you are doing all you can, you know, not to have it (breast cancer).

Others described making a conscious effort to pass these healthy attitudes on to other family members, especially their children.

For many women, knowing about their increased risk and attending the clinic prompted increased vigilance about performing BSE. However, one woman chose not to perform BSE in order to avoid exacerbating her existing anxieties.

Family issues

Some women openly discussed their increased risk with other family members. This commonly resulted in closer relationships with mothers or sisters who had breast cancer or who were also at increased risk. Partners were often described as lacking insight into the women's feelings, which limited the discussion and the support provided. For these women, their increased risk was very much a family affair, involving family members in visits to the clinic and raising their relatives' awareness of cancer.

Having an increased risk of breast cancer doesn't (just) affect you, it affects everybody around you as well.

Women in families where a close relative was suffering from breast cancer or where discussion about breast cancer was generally avoided, described their reluctance to discuss their increased risk with family members. Other women regarded their increased risk very much as their own problem and thought it unnecessary to involve others at this stage.

Two main sources of *emotional support* were described by the women: family and friends, particularly mothers and sisters, and professionals such as the clinic staff and counsellors.

Breast cancer survivors, who tended to be the women's mothers, were also an important source of strength and support.

The women commonly expressed concerns about the implications of their increased risk for their *children*, especially their daughters. Women with young children were predominantly worried about their children's ability to cope if they developed breast cancer. This reflected their own experience of losing their mothers at a very young age. Women with older children described their growing concerns regarding their children's own inherited risk.

...I can cope with sort of having the gene or whatever but it suddenly dawned on me about my own 2 daughters and I think as time's gone on, I felt, God, I hope not. I can cope with it myself but I wonder about my children, maybe that's over the years I've thought that now.

Clinical surveillance

Many women described how their annual *clinic appointments* had become less frequent with a shorter *duration*. Some women were concerned that these changes in service provision added to existing uncertainties and could be damaging to their health. Several women emphasised a need for some alternative form of *continuous support* to compensate for the existing clinical pressures.

I sometimes think it's true what they say, I mean an hour a year is better than nothing, but what happens for the rest of the year. You're out there on your own.

Although several women felt very closely monitored by the current *clinical services*, some women described their concerns about the possible side effects of mammography together with reservations about participating in research trials.

Many women expressed how privileged they felt to be receiving such *specialist care* and how confident they felt both with the expertise of the staff and the equipment. Much importance was placed on the clinical service, in terms of alleviating any anxieties, providing the opportunity for the early detection of breast cancer and informing them of any significant medical advances.

Feelings of *reassurance* both from the clinic and their own general practitioner were frequently voiced, particularly when the women found BSE difficult. They also found that the clinic provided them with a sense of *security* as they were always aware that help was just a phone call away. Many women found this a comfort and an aid to coping with their increased risk.

I think the fact that knowing that you can attend the clinic once a year really makes quite a difference to stopping you from worrying and having the same sort of apprehension, if you like, in the back of your mind, because you always know that although you may check yourself there is always someone else there, you know, to do the extra check for you, just to make doubly certain.

Provision of information

Discussion about the role of *knowledge* in coping with an increased risk uncovered contrasting experiences. Many women found that being informed about breast cancer-related issues had helped them to cope by aiding their decision-making and decreasing anxiety. In contrast, other women felt that this sort of information often added to existing concerns.

Some women suggested it was about *getting a balance* between being informed and increasing worry.

I think it's dangerous. I think people can dwell on things that aren't there and are maybe never going to happen. I think it's very hard to get the balance right and probably very hard when you're trying to provide a service as well.

The women commonly expressed a need for specific *types of information*, particularly up-to-date, professionally approved, detailed information on a variety of topics including the clinical services available (particularly genetic testing), scientific research (concerning breast cancer treatments, current trials and genetics), preventative measures (such as diet), hormone replacement therapy, the oral contraceptive pill and stress management.

There was a widespread positive response to the idea of *presenting* this information via an organised face-to-face meeting which would provide the women with a direct opportunity to ask questions.

I think people these days, they like to be informed, they want to know what's going on and what research is showing. But, you know, to have it explained in a way they can grasp and understand and I think that's a problem with being sent stuff in the post, if people don't understand it, there's nobody to ask or to question. I think that would be the beauty of having an informal type of meeting where people could maybe get the chance to talk to people after the presentations or whatever. I think that would be invaluable.

Written information was seen to be very convenient and a valuable reference, but generally supplementary to gaining information on a face-to-face basis. Other suggestions to be kept informed included a newsletter, web site and Internet news group.

Discussion about *involving the family* uncovered some differences of opinion about who should attend an organised meeting. Several women thought that all family members should attend, others felt that it would only be beneficial for their partners and some expressed their reluctance to attend if other family members were invited. These women preferred to relay any relevant information to their families.

Many women described problems contacting the clinic and would welcome some form of *immediate telephone contact*, such as a telephone help-line, for gaining instant advice from a specialist clinician. Several women felt that access to such a service would provide them with an extra source of reassurance.

Peer support

Many women suggested that it would be beneficial to have some form of contact with *other women in the same situation* either face-to-face, by telephone or via an Internet chat room. They felt that it would be helpful to share their experiences in a support group setting or as part of a social event.

... if I was to go to some sort of group meeting where people were in a similar position to me, I suspect that's the group where I might feel comfortable and be able to say, 'Look maybe I am worried', where I might not say that at home because if I have had somebody who's had breast cancer... I certainly am the one being terribly positive with her (my mother) and therefore would not want to take her along and hear her say, 'maybe I have been

worried', so I'd quite like, I think, the idea of empathy with a group with similar circumstances.

Feedback questionnaire

All 25 participants returned completed questionnaires. Two questions asked participants about the extent to which knowing about their increased risk had affected their lives in positive ways (e.g. encouraging them to maintain a healthy lifestyle) or negative ways (e.g. causing them worry). With respect to positive effects, 19 participants (76%) reported *not at all/a little* and 6 (24%) reported *quite a bit/very much*. With respect to negative effects, the corresponding numbers were 23 (92%) and 2 (8%). No participants rated the negative effects as *very much*. More than half of the participants had found it *a little* or *quite a bit* difficult to cope with the knowledge of their increased risk ($n = 14$; 56%).

All participants reported that they would like to be provided with updated information on a variety of breast cancer-related topics ($n = 25$; 100%). A majority would like advice/information on stress management strategies ($n = 19$; 76%), the opportunity to meet up with other women in the same situation ($n = 22$; 88%) and the opportunity to have any questions answered outside of the clinic time ($n = 23$; 92%). Approximately half of the participants ($n = 12$; 48%) would like to be provided with a service for other family members. With respect to the format of any additional services, 14 participants (56%) indicated a general preference for written materials rather than personal contact and 60% ($n = 15$) preferred organised meetings rather than one-to-one sessions.

Although 23 of the 25 participants had not taken part in a telephone conference call before, only one woman did not feel comfortable about sharing her experiences in the telephone focus group. Most of the participants found it *quite* or *very* easy to make their opinions known ($n = 21$; 84%) and 76% ($n = 19$) thought that the moderator handled the discussion *very well*. Twenty participants (80%) found it *quite a bit* or *very helpful* to share their experiences with women in the same situation and 84% ($n = 21$) of participants rated their general experience of taking part in a telephone focus group as *good* or *excellent*.

Both of the participants who reported that a breast cancer gene had been identified in their

family stated that they had been tested for this faulty gene of whom one was a carrier and one was still waiting for their result.

DISCUSSION

The telephone focus group methodology used in this study provided a rich source of information about the long-term psychosocial consequences of genetic risk counselling for breast cancer. As the information gained from later focus groups began to reiterate that collected from earlier groups, it encouraged us to believe that we had elicited the full range of issues for these women. The qualitative data were supported by the quantitative results of the feedback questionnaire. Before considering the main findings and implications of our results, several methodological observations should be noted.

The low response (47%) and participation (36%) rates were disappointing. This may in part be explained by the practical difficulties of gaining accurate contact information for women who only attend the clinic on an annual basis and the relatively short time frame offered for reply and participation. Scepticism among the women about the use of such a novel methodology may also have acted as a barrier towards participation. Therefore, the 25 participants may not be representative of the other 45 women invited to participate. Although these two groups did not differ significantly on the six demographic measures assessed, the participants may be biased in terms of the coping strategies they used (e.g. the invitation to participate may act as a breast cancer cue, stimulating an avoidant response) and may be unrepresentative in terms of psychological distress (e.g. highly distressed individuals may not have responded to the invitation). However, the aim of exploratory focus group research is not to generalise the findings to a larger sample, but to represent a range of participant views (Vaughn *et al.*, 1996). The data collected did encompass a wide range of opinions and experiences indicating that they are likely to reflect the important issues in this group.

Despite the low participation rate, the telephone focus group methodology was shown to be a very useful and convenient means of accessing a wide range of experiences. With thorough preparation of the moderator guide and training in

facilitating telephone conferences, the groups were relatively easy to organise and conduct and were very cost-effective. Participant feedback about the telephone focus groups was extremely positive. Any initial scepticism among participants was quickly dispelled as the anonymity of the telephone conferencing system made them feel less inhibited about sharing their experiences. Many participants expressed how beneficial they found this experience and were keen to participate again or follow up the group with a face-to-face meeting. There was also evidence that some women had started to bond with other members of the group despite the lack of face-to-face contact: as one woman commented, 'I enjoyed the experience and even felt momentarily "bereft" when I said goodbye to the other participants'.

This study provides an important insight into the women's experience of the long-term effects of knowing about their increased risk on their everyday life. Firstly, there was wide variation in the anxiety and distress that these women described experiencing in the years since they first attended the clinic. A few participants reported experiencing severe worry and intrusive thoughts on a daily basis. There is a clear need to assess the prevalence and specificity of psychological morbidity in this population to enable interventions to be targeted appropriately. Secondly, anxiety and distress were often described as fluctuating over time in response to breast cancer-related cues, such as approaching the time of a clinic appointment. Previous research provides evidence that levels of acute psychological distress in women with a family history of breast cancer are high immediately prior to routine mammography and are lowered after receiving normal results (Valdimarsdottir *et al.*, 1995). Our findings suggest that the impact of such cues may be related to the individual's level of chronic anxiety and distress. The possible relationship between chronic distress and a heightened sensitivity to breast cancer cues requires further investigation in a larger sample.

There was evidence that the women in this study drew on a number of important internal and external coping resources, including positive cognitions, knowledge about breast cancer-related issues, clinical surveillance and family members. Of the range of cognitive and behavioural coping strategies that were described, particular strategies, such as cognitive avoidance, were described as minimising anxiety and distress over time, which may suggest an adaptive role in the

long-term. Behavioural coping strategies, such as excessive reassurance seeking, were used in times of acute anxiety and distress. The use of behavioural coping strategies associated with adopting a healthy lifestyle was seen to be adaptive by promoting a degree of perceived control over a woman's increased risk. The findings of this study then highlight the incidental benefits of including a general health behaviour component as part of an educational intervention. Although the biological role of particular health behaviours in the prevention of breast cancer remains unclear, these behaviours may represent adaptive coping resources to be accessed in times of personal stress (Ingledew *et al.*, 1996). The long-term role of specific coping strategies, particularly cognitive avoidance, requires further investigation in terms of specific outcomes such as psychological distress and cancer worry. Interventions can then be aimed at promoting the use of those strategies that are shown to be adaptive in the long-term.

Every woman in this study indicated at least one support need that was not being met by the existing clinical service where the only form of support is limited to an annual clinic appointment focusing on breast cancer screening. This need for additional support services is further strengthened by the decreasing frequency and limited duration of these follow-up appointments. Of top priority was the provision of information on a wide variety of breast cancer-related topics. There was a general preference for this information to be presented by an expert via a group meeting with supplementary written materials. To date, there have been a number of intervention studies in women with a family history of breast cancer (e.g. Gagnon *et al.*, 1996; Lerman *et al.*, 1996; Cull *et al.*, 1998; Schwartz *et al.*, 1998; Audrain *et al.*, 1999; Kash *et al.*, 1999; Wellisch *et al.*, 1999). These have varied greatly in terms of their aims (e.g. reducing psychological distress, improving adherence to BSE), sample (e.g. first-degree relatives of recently diagnosed breast cancer patients, high-risk women maintained on regular clinical surveillance) and format of the intervention (e.g. newsletter, problem-solving training). Of particular interest to our research are the recent psycho-educational group interventions in women at high-risk of developing breast cancer (i.e. Kash *et al.*, 1999; Wellisch *et al.*, 1999). The preliminary results of these studies in terms of reducing psychological morbidity and improving knowledge are encouraging. Research is needed to establish

whether women at increased risk of breast cancer who have been maintained on regular clinical surveillance for a number of years would participate in and benefit from psycho-educational intervention.

In summary, this study provides qualitative evidence of between- and within-individual differences in terms of anxiety, distress and the coping strategies adopted and between-individual variation in the impact of breast cancer cues. The findings of this study suggest that there is a need for psychological intervention for a minority of participants who reported experiencing chronic psychological symptoms. However, the findings also highlight a need for intervention that may not only be confined to those suffering from psychological morbidity. Although the participants represented approximately one third of the women invited to participate, they all expressed a need for updated information from professional sources on breast cancer-related issues. The clinical implications that have arisen from these main findings warrant further quantitative research in a larger sample of women living with an increased risk of breast cancer.

ACKNOWLEDGEMENTS

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Appendix II

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FOCUS GROUP MODERATOR GUIDE:
LONG-TERM COPING WITH AN
INCREASED RISK OF BREAST CANCER

Whilst waiting for participants to join the conference, break up the silence with a general chat and welcome. Check participants have a pen & paper handy.

Before we begin, can I just check that you are all here.

Firstly, I'd like to welcome you all to this telephone discussion group and to thank you for giving up your time to help this research.

As you know, my name is Sally and I will be leading today's discussion.

Before we start, here are just a few ground rules to ensure that the discussion runs as smoothly as possible:

- Try to remember to identify yourself before you speak just using your *first* name.
- Although I would like everyone to contribute to the discussion, you do not need to answer every question.
- If you find that you are always the first person to speak, then hold back and let someone else have a chance. On the other hand, don't be shy, make your opinions known.
- You do not need to address all your comments directly to me. Feel free to respond directly to what someone else has said.
- Please be honest about your opinions.
- Remember that there are no right or wrong answers.
- As we have limited time for this group discussion (which will be about an hour), I may need to stop you to redirect the discussion. 5 minutes before the end of the session we should receive a warning from the telephone operator.
- Have you got a pen & paper handy to take down a telephone number. If for any reason you leave the discussion group before we have finished and you would like to rejoin the group, please ring this number and then they will call you back to reconnect you to the group.

- (Some of you taking part in this discussion group have the call-waiting facility on your phone. If you or any other members of the group hear the signal, please try to ignore it as much as possible).
- If this is the first time you have taken part in a telephone conference call it may feel quite strange at first. But don't worry, it shouldn't take too long for you to feel comfortable speaking in this situation.

You have all been invited to take part in this telephone discussion group as you have known, for a number of years now, about the increased risk of breast cancer in your family.

With the benefit of your experience we are trying to improve our understanding about what it is like for women today who are trying to come to terms with the information that they have an increased risk of breast cancer in their family and who are working out how they are going to live with it.

As we would like to offer some new services to women like yourselves in the future, we would be very interested to hear your opinions about the sorts of things that could be of help and I'll ask you about this later on.

Has anyone got any questions about the discussion before we begin?

To begin with, I would like to ask you to introduce yourselves to the group using your *first* names only, to say roughly how long you have been attending the Ardmillan clinic and to just describe where you are sitting so that the other members of the group can picture you.

I'll begin.....

EFFECT

We are going to begin today's discussion by considering what sort of *long-term* impact knowing about an increased risk of breast cancer in the family has had on your everyday lives. We will be looking at whether it has affected the way you do things, the way you think, the way you feel and your relationships with other people in your family. We are interested to hear about any positive changes as well as any negative changes that may have occurred over the years.

- 1. Has knowing about an increased risk of breast cancer in your family, changed the way you do things?**

For example, has it changed the way you look after your own or your family's health?

PROBE FOR:

⇒ Has it affect your plans for or decisions about the future?

- 2. Has knowing about an increased risk of breast cancer in your family changed the way you think about things?**

For example, has it changed your attitudes to any health issues?

PROBE FOR:

⇒ Has it changed your priorities in life?

⇒ Has it tended to play on your mind at all?

- 3. How has knowing about an increased risk of breast cancer in the family made you feel?**

For example, does it cause you much worry or upset in your everyday life or does it make you feel more positively about your life?

- 4. Has knowing about an increased risk of breast cancer in the family affected your relationships with other people in your family?**

It may be useful to think about this in terms of:

Who did you tell about the increased risk of breast cancer in your family?

What did you tell them?

Did this affect your relationship with them?

COPING

So we've just talked about the how knowing about an increased risk of breast cancer in the family can have a *long-term* impact on different aspects of your everyday life. Now if we move on to the next part of the discussion, I would like to draw on your years of experience to try to anticipate the hardest things that a women who has recently learned of an increased risk of breast cancer in her family may have to face over the next few years as she goes about her daily life.

5. From your years of experience, what do think are the hardest things to cope with?

This may involve any thoughts you have had, feelings about the situation or things you have had to do?

6. Can you say what has helped you to cope?

This could be something you have done to help yourself or something someone else has done to help you?

And these things that have helped could be practical things, things you have thought about the situation or any feelings you might have had.

7. Overall, would you say that knowing about an increased risk of breast cancer in the family has had a positive or negative effect on your life?

SERVICES

If we now move on to the last section where we will be discussing the possible services that could be of benefit to women who find themselves in your situation in the future. We are aware that the clinics are currently under a lot of pressure and therefore enough time for you to get information or have any questions answered during your yearly appointments may not always be available. This is just one of the needs that we are interested in fulfilling in association with the Ardmillan clinic. We would first like to consider what a new service should include and secondly we would like to find out how we can best provide it.

8. If you look back on the number of years that you have known about the increased risk of breast cancer in your family, do you think that anything else could have been provided to help you to cope?

For example, would you be interested in a service that provided you with updated information ? If so, on what sorts of topics?

PROBE FOR:

- ⇒ Would you be interested in having the direct opportunity to have any questions answered outside of your clinic visits?
- ⇒ What about things to help you cope with any stress you may be experiencing?
- ⇒ What about the opportunity to meet up with other women in the same situation?
- ⇒ What about something for other family members?

9. As we have just discussed what you would like a new service to include, we would now like to find out the best way we can provide such a service. We would like you to think about how you would like these services to be provided?

For example, what do you think about an organised meeting as opposed to a one-to-one session?

PROBE FOR:

- ⇒ What do you think about some sort of personal contact either face-to-face, on the telephone or via e-mail?
- ⇒ Would the time, location or frequency of services be important for you?
- ⇒ What do you think about information being provided as leaflets or via the Internet?

As this discussion now comes to a close, I would like to thank you all again for your valuable contributions to this research.

I would like to remind you that you will be receiving a short questionnaire in the post in the next few days just to clarify some of the issues raised here and to tell us what you think about these discussion groups. We would be very grateful if you would return this in the stamped addressed envelope provided as soon as possible.

If we now go round in turn to say goodbye to the group and then I will say goodbye before we all put the phone down together.

TELEPHONE DISCUSSION GROUP:
PARTICIPANT FEEDBACK QUESTIONNAIRE

First name:.....

Telephone discussion group no. :.....

Thank you for taking part in one of the telephone discussion groups about coping with an increased risk of breast cancer. You made an extremely valuable contribution to this research.

As I mentioned at the end of the telephone discussion group, we would be very grateful if you would take a few minutes to complete this short questionnaire and return it in the enclosed stamped addressed envelope as soon as possible.

We do appreciate that you may have already completed several questionnaires as part of your annual follow-up at the Ardmillan Familial Breast Cancer Clinic and would like to thank you for this information. Although some of the questions in this questionnaire may be very similar to some that you have previously answered, we feel that it is important to gain your opinions after you have taken part in the telephone discussion group.

This questionnaire allows you to provide a more personal account of some of the opinions you may have expressed in the discussion group. We are also interested to hear what you thought about taking part in a telephone discussion group as this may be useful for future research. I would welcome any additional comments you may have about the discussion group or any of the issues raised during the session.

Thank you once again for your time,

Yours Sincerely

A handwritten signature in cursive script that reads "Sally Appleton".

Sally Appleton
Postgraduate Psychologist.

Although the questionnaires that you have kindly completed for us every year have asked you about how you have been getting on during the previous year, we would now like to put all this information together and find out about your overall impression of being at increased risk of breast cancer over the number of years that you have been attending the Ardmillan Familial Breast Cancer Clinic.

Please circle the answer that is most appropriate for you for each question.

1. How much has knowing about an increased risk of breast cancer in your family changed the way you do things ?

Not at all A little Quite a bit Very much

2. How much has knowing about an increased risk of breast cancer in your family changed the way you think about your life in general ?

Not at all A little Quite a bit Very much

3. How much has knowing about an increased risk of breast cancer in your family changed the way you generally feel ?

Not at all A little Quite a bit Very much

4. How much has knowing about an increased risk of breast cancer in your family changed your relationships with other people in your family ?

Not at all A little Quite a bit Very much

Some of these changes may have had a positive effect on your life such as encouraging you to maintain a healthy lifestyle, whilst others may have had a negative effect on your life such as causing you to worry a lot more.

5. To what extent has knowing about an increased risk of breast cancer in your family had a *positive* effect on your life ?

Not at all A little Quite a bit Very much

6. To what extent has knowing about an increased risk of breast cancer in your family had a *negative* effect on your life ?

Not at all A little Quite a bit Very much

7. Have you found it difficult to cope with knowing that there is an increased risk of breast cancer in your family ?

Not at all A little Quite a bit Very much

8. Has anything been particularly difficult for you to cope with ?

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We are interested to find out what additional services you would like to receive to help you cope with being at increased risk so that we can offer these to women in your situation in the future.

9. Would you like to be provided with:

a) Updated information ? Yes No

If you answered YES to the above question, please list the following topics of information in order of preference from 1 = would most like to 8 = would least like. If you answered NO to the above question, please continue to part 9b.

- i) Current breast cancer research** ☐
- ii) Breast cancer screening** ☐
- iii) Breast cancer treatment** ☐
- iv) Breast cancer surgery** ☐
- v) Other forms of cancer (e.g. ovarian cancer)** ☐
- vi) Hormone Replacement Therapy** ☐
- vii) Maintaining a healthy lifestyle** ☐
- viii) Another topic (please specify)** ☐
.....

b) Things to help you cope with any stress you may be experiencing ? Yes No

c) The opportunity to meet up with other women in the same situation ? Yes No

d) Something for other family members ? Yes No

e) The opportunity to have any questions answered outside of the clinic time ? Yes No

10. If you would like any of these additional services, how would you like them to be provided ?

Please indicate which one of the following pairs of options you would prefer by ticking the appropriate box.

Would you prefer:

a) written materials *or* ☐
personal contact ☐

b) one-to-one sessions *or* ☐
organised meetings ☐

c) face-to-face contact *or* ☐
telephone contact ☐

11. Do you have access to the Internet/ e-mail ? Yes No

If you answered YES, would this be a convenient way to send you/give you access to information ? Yes No

We would now like to find out what you thought about taking part in the telephone discussion group as we may consider using telephone discussion groups in future research.

11. Did you find it easy to make your opinions known ?

Not at all A little Quite a bit Very much

12. Do you think the leader handled the discussion well ?

Not at all A little Quite a bit Very much

13. Did you feel comfortable about sharing your experience in a telephone discussion group ?

Not at all A little Quite a bit Very much

14. Did you find it helpful to share your experience with women in the same situation ?

Not at all A little Quite a bit Very much

15. How would you rate your general experience of taking part in the telephone discussion group ?

Poor Fair Good Excellent

16. Was this the first time you had taken part in a telephone conference call (i.e. where you are able to talk to several people at once) ?

Yes No *(If you answered NO, approximately how many times have you done this before and do you use telephone conference calls as part of your job or home life)*

.....
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When evaluating what you have told us, it is important for us to know whether or not you have received genetic testing for breast cancer. Therefore, we would be grateful if you would answer the following questions.

17. Has a faulty breast cancer gene been identified in your family ? Yes No

18. Have you been tested for this faulty gene ? Yes No Not Applicable

**19. Have you had the results of the genetic test yet ? Yes No Not
Applicable**

20. If so, were you found to carry the faulty gene ? Yes No Not Applicable

We would welcome any further ideas you have about the telephone discussion group and any of the issues that we discussed.

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**THANK YOU VERY MUCH FOR YOUR TIME
PLEASE RETURN YOUR COMPLETED QUESTIONNAIRE IN THE
ENCLOSED STAMPED ADDRESSED ENVELOPE AS SOON AS
POSSIBLE**

GUIDELINES FOR TELEPHONING PARTICIPANTS PRIOR TO THEIR SCHEDULED DISCUSSION GROUP

When:

- Telephone each participant a few days before their scheduled discussion group.

Why:

- To ensure that they are still able to participate in the scheduled group as they may have received their letter of confirmation up to several weeks previously.
- To introduce myself to each participant individually and familiarise them with my voice.
- To give them an opportunity to ask me any questions about the telephone discussion group on a one-to-one basis.
- To describe the procedure and structure of the telephone discussion group.
- To warn them that they may initially feel slightly uncomfortable with speaking in a telephone group.
- To find out if any of the participants have a call-waiting service on their phones.

How:

- My name is Sally Appleton and I am a postgraduate psychologist working for the Imperial Cancer Research Fund.
- Thank you for agreeing to take part in my research. I am just phoning to check that you are still able to take part in the telephone discussion group on at
- Have you got a few minutes to let me give you more of an idea about the telephone discussion group and to give you the opportunity to ask me any questions?
- I'd just like to tell you a bit about why we decided to do this research using telephone discussion groups.

Why are we using discussion groups?

Discussion groups allow their participants to respond to what each other has said and not just to answer a set list of questions. This is especially important for generating new ideas as we are doing in this study.

Why are we doing this over the phone?

As all the women that are taking part in this study live in quite a large area, it seems a lot less of a burden on your time to ask you to take part in this research over the phone, rather than you having to travel to a meeting. We also feel that some participants may feel more comfortable speaking over the phone, than in a face-to-face discussion.

- As you know you will be telephoned on at to join the group discussion. There will be myself and about 4 other women including yourself.

- I will start off by giving a brief introduction to the group which will include setting some ground rules for the discussion. Then I will ask you to introduce yourselves to the group using your first names only.
- During the main discussion I will pose a number of questions to the whole group which will cover 3 main themes. These are:
 1. How the knowledge of being at increased risk of breast cancer has affected your life.
 2. How you have been coping with this knowledge.
 3. What sort of services you think would help you to cope.
- I will also summarise what the group has said at appropriate points during the discussion.
- The whole session should last about an hour.
- It will make it easier to identify who has said what if you remember to say your first name every time before you speak, just something like "It's Sally here".
- Have you taken part in a telephone discussion group before or something similar such as talking to a number of people on the phone at the same time?
If you haven't then it may feel a bit strange at first - but you should gradually feel more comfortable as the discussion goes on.
If you have done this before, what was it initially like for you?
- Do you have a call-waiting facility on your phone? What does this sound like? What does the other person hear? Please ignore the signal and try to let it distract you at least as possible. Would you be expecting any calls at that time? Would you be able to let those people know that you are taking part in a telephone discussion group at that time and the group may be disturbed if they try to get in touch with you?
- Do you have any questions you would like to ask me?
- Thanks for your time and I look forward to speaking to you on

Follow-up of long-term attendees at the Ardmillan Clinic

QUESTIONNAIRE PACK

ID Number:

PRIVATE AND CONFIDENTIAL

This booklet should take approximately 30 minutes to complete.

Please don't think for too long about each of your answers but give your immediate response. There are no right or wrong answers to any of the questions. Please try to answer all of the questions.

Please note, the questions are printed on both sides of the page.

If you have any queries about the study or the questionnaire booklet, do not hesitate to contact Sally Appleton on the telephone number below.

When you have finished, please return the booklet as soon as possible in the FREEPOST envelope provided.

THANK YOU VERY MUCH FOR YOUR HELP

For the attention of:

Sally Appleton, Imperial Cancer Research Fund, Postgraduate Psychologist, Department of Clinical Psychology, Outpatient Building, Western General Hospital, Edinburgh EH4 2XU
Tel: 0131 537 1838 E-mail: S.Appleton@icrf.icnet.uk

Please fill in today's date: (day/month/year) __/__/____

We would like to start by asking you some general questions about yourself. Please answer all questions.

1. Date of birth: (day/month/year) __/__/____

2. Are you: (please tick)

Single	<input type="checkbox"/>
Married/living with a partner	<input type="checkbox"/>
Divorced/separated	<input type="checkbox"/>
Widowed	<input type="checkbox"/>

3. How many children do you have? _____

(If you have children, please give the age and sex of each child)

1 st child:	Age	____	Male	____	Female	____
2 nd child:	Age	____	Male	____	Female	____
3 rd child:	Age	____	Male	____	Female	____
4 th child:	Age	____	Male	____	Female	____

(please continue on a separate piece of paper if necessary)

4. Please tick the situation which best describes your education:

Schooling until age 16	<input type="checkbox"/>
School/further education/training until age 18	<input type="checkbox"/>
Further education or training after age 18	<input type="checkbox"/>
University graduate	<input type="checkbox"/>

5. Ethnic group: (please tick)

White []	Black-Caribbean []	Black-African []	Black-other []	(please describe) _____
Indian []	Pakistani []	Bangladeshi []	Chinese []	

Any other ethnic group (please describe) _____

6. Occupation: (please tick)

Full-time employment	<input type="checkbox"/>
Part-time employment	<input type="checkbox"/>
Unemployed	<input type="checkbox"/>
Retired	<input type="checkbox"/>
Home duties	<input type="checkbox"/>

7. Do you currently suffer from any medical conditions? Yes ☐
No ☐

(If yes, please specify)

8. Have you ever been treated for nervous or emotional problems such as anxiety or depression in the past at any time? Yes ☐
No ☐

(If yes, please give details)

9. Have you ever had an admission to hospital for nervous problems? Yes ☐
No ☐

(If yes, please give details)

We know that you will have been asked in the past for information about your family history of breast cancer and that this can be upsetting, but it would helpful if we could have up-to-date information about your family history.

10. How many of your relatives have been diagnosed with breast cancer? _____

11. What relation was this person to you (e.g. mother, sister), at what age were they first diagnosed with breast cancer and how are they now? (please write the relationship, the age at diagnosis and circle the most appropriate response)

		Alive and well	Alive but unwell	Died from breast cancer	Died from other causes
1 st relative:	Age at diagnosis	1	2	3	4
2 nd relative:	Age at diagnosis	1	2	3	4
3 rd relative:	Age at diagnosis	1	2	3	4
4 th relative:	Age at diagnosis	1	2	3	4
5 th relative:	Age at diagnosis	1	2	3	4

(please continue on a separate piece of paper if necessary)

12. How many of these relatives were personally known to you? _____

It would be helpful if you could give us some information about your attendance at the Ardmillan Familial Breast Cancer Clinic (If you are unsure of the exact dates then please just give the month and year)

13. a) When did you last attend the Ardmillan Familial Breast Cancer Clinic?

(day/month/year) _ _ / _ _ / _ _ _ _

b) When is your next appointment at the Ardmillan Familial Breast Cancer Clinic?

(day/month/year) _ _ / _ _ / _ _ _ _

*We want to learn what people understand about their risk of developing breast cancer.
Please answer the following questions by circling a number or ticking the appropriate box.*

14. Do you think that your risk of ever developing breast cancer is:

- a. Lower than the general population ☐
- b. The same as the general population ☐
- c. Slightly higher than the general population ☐
- d. Much higher than the general population ☐

15. How likely do you feel it is that you will ever develop breast cancer?

Very Unlikely	Unlikely	Likely	Very likely	Inevitable
1	2	3	4	5

16. Since you first started attending the Ardmillan Familial Breast Cancer Clinic do you think that your risk of ever developing breast cancer has:

- a. increased ☐
- b. decreased ☐
- c. stayed the same ☐
- d. not sure ☐

17. How much control do you feel you have over whether you ever develop breast cancer?

None at all	A bit	Moderate	A lot
1	2	3	4

18. *We are interested to know if you have had any medical complaints, and how your health has been in general over the past few weeks. Please answer ALL the questions on the following pages simply by circling the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.*

It is important that you try to answer ALL the questions. Thank you very much for your co-operation.

HAVE YOU RECENTLY

been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less than usual
felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

HAVE YOU RECENTLY

been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual

19. *We want to learn more about how people cope with worrying events in everyday life. We know that everyone is different so there are no right or wrong answers. From what you know of yourself and your own reactions to worrying events in the past, please try to predict your reactions to the following:*

- a. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Tick **all** of the statements that might apply to you.

- ☐ I would ask the dentist exactly what he or she was going to do
- ☐ I would take tranquilizers or have a drink before going
- ☐ I would try to think about pleasant memories
- ☐ I would want the dentist to tell me when I would feel pain
- ☐ I would try to sleep
- ☐ I would watch the dentist's movements and listen for the sound of the drill
- ☐ I would watch the flow of water from my mouth to see if it contained blood
- ☐ I would do mental puzzles in my mind

- b. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor had turned in an evaluation of your work for the past year. The decision about lay-offs has been made and it will be announced in several days. Tick **all** of the statements that might apply to you.

- ☐ I would talk to my fellow workers to see if they knew anything about the supervisor's evaluation of me.
- ☐ I would review the list of duties for my present job and try to figure out if I had fulfilled them all.
- ☐ I would go to the cinema to take my mind off things.
- ☐ I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his or her opinion of me.
- ☐ I would push all thoughts of being laid off out of my mind
- ☐ I would tell all my family and close friends that I'd rather not discuss my chances of being laid off
- ☐ I would try to think which employees in my department might be thought by the supervisor to have done the worst job
- ☐ I would continue doing my work as if nothing special was happening

20. *The following statements describe different ways of reacting to situations. Please read each one carefully and circle the one alternative which you feel is most like you. The alternatives are as follows:*

(N) Never	(S) Sometimes	(O) Often	(A) Always	
1. I tend to give up easily when I don't clearly understand a situation.	N	S	O	A
2. When I go shopping, I like to have a list of exactly what I need.	N	S	O	A
3. I feel better about myself when I know that I have done all I can to plan my future accurately.	N	S	O	A
4. Sudden changes make me feel upset.	N	S	O	A
5. When making a decision, I am deterred by the fear of making a mistake.	N	S	O	A
6. When uncertain, I act very cautiously until I have more information about the situation.	N	S	O	A
7. I like to have things under control.	N	S	O	A
8. When the future is uncertain, I generally expect the worst to happen.	N	S	O	A
9. Facing uncertainty is a nerve-racking experience.	N	S	O	A
10. I get worried when a situation is uncertain.	N	S	O	A
11. Thinking about uncertainty makes me feel depressed.	N	S	O	A
12. Uncertainty frightens me.	N	S	O	A
13. When I feel uncertain about something, I try to weigh up rationally all the information I have.	N	S	O	A
14. Before making any changes, I need to think things over thoroughly.	N	S	O	A
15. I prefer to stick to tried and tested ways of doing things.	N	S	O	A
16. I like to have my weekends planned in advance.	N	S	O	A
17. When I feel a situation is unclear, I try to do my best to resolve it.	N	S	O	A
18. I like to know exactly what I'm going to do next.	N	S	O	A
19. When facing an uncertain situation, I tend to prepare as much as possible and then hope for the best.	N	S	O	A

(N) Never	(S) Sometimes	(O) Often	(A) Always	
20. I feel relieved when an ambiguous situation suddenly becomes clear.	N	S	O	A
21. When I feel uncertain, I try to take decisive steps to clarify the situation.	N	S	O	A
22. When I can't clearly discern situations, I get apprehensive.	N	S	O	A
23. When I'm not certain about someone's intentions towards me, I often become upset or angry.	N	S	O	A
24. When uncertain about what to do next, I tend to feel lost.	N	S	O	A
25. I feel anxious when things are changing.	N	S	O	A
26. I try to have my life and career clearly mapped out.	N	S	O	A
27. When a situation is unclear, it makes me feel angry.	N	S	O	A
28. I like things to be ordered and in place, both at work and at home.	N	S	O	A
29. I get really anxious if I don't know what someone thinks about me.	N	S	O	A
30. I am hesitant when it comes to making changes.	N	S	O	A
31. I like to plan ahead in detail rather than leaving things to chance.	N	S	O	A
32. Before I buy something, I have to view every sample I can find.	N	S	O	A

21. The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help and support in the manner described. Give each person's initials and their relationship to you (see example). Do not list more than one person next to each of the numbers beneath each question. Do not list more than nine people per question.

For the second part, using the scale below, circle how satisfied you are with the overall support you have.

6	5	4	3	2	1
Very Satisfied	Fairly Satisfied	A little Satisfied	A little <u>Dissatisfied</u>	Fairly <u>Dissatisfied</u>	Very <u>Dissatisfied</u>

If you have no support for a question, tick the words 'No one', but still rate your level of satisfaction. The example below has been completed to help you. All your responses will be kept confidential.

Example

Who do you know whom you can trust with information that could get you in trouble?

- i)

No one

1) JA (sister)

2) DE (friend)

3) AF (friend)

4) MA (father)

5) AC (employer)

6)

7)

8)

9)
- ii)

How satisfied?

6

5

4

3

2

1

a) Whom can you really count on to distract you from your worries when you feel under stress?

- i)

No one

1)

2)

3)

4)

5)

6)

7)

8)

9)
- ii)

How satisfied?

6

5

4

3

2

1

b) Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

- i)

No one

1)

2)

3)

4)

5)

6)

7)

8)

9)
- ii)

How satisfied?

6

5

4

3

2

1

c) Who accepts you totally, including both your worst and best points?

i)	No one						
	1)	4)	7)	9)			
	2)	5)	8)				
	3)	6)					
ii)	How satisfied?	6	5	4	3	2	1

d) Whom can you really count on to care about you, regardless of what is happening to you?

i)	No one						
	1)	4)	7)	9)			
	2)	5)	8)				
	3)	6)					
ii)	How satisfied?	6	5	4	3	2	1

e) Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

i)	No one						
	1)	4)	7)	9)			
	2)	5)	8)				
	3)	6)					
ii)	How satisfied?	6	5	4	3	2	1

f) Whom can you count on to console you when you are very upset?

i)	No one						
	1)	4)	7)	9)			
	2)	5)	8)				
	3)	6)					
ii)	How satisfied?	6	5	4	3	2	1

22. The following questions ask about any concerns you may have regarding breast cancer. For each question please circle the answer you think best describes how worried you have been in the past week about the following subjects:

IN THE PAST WEEK, HOW WORRIED HAVE YOU BEEN ABOUT:

	Not at all worried	A little worried	Moderately worried	Very worried
a. ...developing breast cancer anytime now?	1	2	3	4
b. ...developing breast cancer in the future?	1	2	3	4
c. ...the possibility of having to make future decisions about your increased risk such as genetic testing or prophylactic surgery?	1	2	3	4
d. ...the frequency of your appointments at the Ardmillan Familial Breast Cancer Clinic?	1	2	3	4
e. ...something else concerning your increased risk of developing breast cancer? (please specify) _____ _____	1	2	3	4

Answer the following 2 questions only if you have children:

IN THE PAST WEEK, HOW WORRIED HAVE YOU BEEN ABOUT:

f. ...dying from breast cancer and leaving your children?	1	2	3	4
g. ...your children's own risk of developing breast cancer?	1	2	3	4

23. We are interested in how people think about their risk of breast cancer. Please circle the appropriate number to indicate how frequently these comments were true for you **during the past week**.

If you have not thought about your risk of breast cancer **in the past week**, please tick this box and go on to the next page.

I have not thought about the risk of breast cancer
(If you have ticked this box, go on to the next page)

☐

		Not at all	Rarely	Sometimes	Often
a.	I thought about it when I didn't mean to	1	2	3	4
b.	I avoided letting myself get upset when I thought about it or was reminded of it	1	2	3	4
c.	I tried to remove it from memory	1	2	3	4
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind	1	2	3	4
e.	I had strong waves of feelings about it	1	2	3	4
f.	I had dreams about it	1	2	3	4
g.	I stayed away from reminders of it	1	2	3	4
h.	I felt as if it wasn't real	1	2	3	4
i.	I tried not to talk about it	1	2	3	4
j.	Pictures about it popped into my mind	1	2	3	4
k.	Other things keep making me think about it	1	2	3	4
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	1	2	3	4
m.	I tried not to think about it	1	2	3	4
n.	Any reminder brought back feelings about it	1	2	3	4
o.	My feelings about it were sort of numb	1	2	3	4

24. *We are interested to find out whether you have experienced anything in the past week that has prompted you to think about your risk of developing breast cancer.*

IN THE PAST WEEK *(please tick each box as appropriate)*

- a) have you read, watched or listened to anything about breast cancer ☐
- b) have you examined your breasts ☐
- c) have you attended the Ardmillan Familial Breast Cancer Clinic ☐
- d) have you had a breast biopsy or related medical investigation ☐
- e) have you been waiting for the results of a mammogram or breast biopsy ☐
- f) have you received the results of a mammogram or breast biopsy ☐
- g) have you had any significant family events such as the birthday of a deceased relative who died from breast cancer ☐
- h) have you spoken to a close relative or friend about your own risk of breast cancer ☐
- i) has a close relative or friend been diagnosed with breast cancer or is undergoing treatment ☐
- j) other ☐

25. We recognise that among women like yourself who have been attending the clinic for a number of years, there may be a need for up-to-date information from experts on topics related to your increased risk of breast cancer. We would like to find out which topics most people would be interested in as we hope to provide this information as part of a future study.

WOULD YOU BE INTERESTED IN INFORMATION ABOUT...

(please tick where appropriate)

- a) Scientific research concerning breast cancer genetics? ☐
- b) Scientific research concerning breast cancer screening? ☐
- c) Scientific research concerning breast cancer treatment? ☐
- d) Research conducted at the Ardmillan Familial Breast Cancer Clinic? ☐
- e) Genetic testing? ☐
- f) Prophylactic surgery? ☐
- g) Hormone Replacement Therapy (HRT)? ☐
- h) The oral contraceptive pill? ☐
- i) Maintaining a healthy lifestyle? ☐
- j) Ways to help you deal with any stress you may be experiencing? ☐
- k) Another topic? *(please specify)* ☐

IF WE WERE TO OFFER THE FOLLOWING AS PART OF A FUTURE STUDY, WOULD YOU BE INTERESTED IN ...*(please tick where appropriate)*

- l) Receiving written information? ☐
- m) A group meeting in Edinburgh (**only for women attending the clinic**) where experts would present the information and be available to answer any questions? ☐
- n) A group meeting in Edinburgh (**for women attending the clinic and their families**) where experts would present the information and be available to answer any questions? ☐

- o) Group discussions with other women in the same situation **by telephone** where expert information would be presented and you would have the opportunity to discuss the information as a group and ask any questions (you would be telephoned at home at a time to suit your convenience)? ☐
- p) None of the above options? ☐

IF ANY OF THE ABOVE GROUPS WERE OFFERED,
WHEN WOULD BE MOST CONVENIENT FOR YOU? *(please tick where appropriate)*

- q) Mornings ☐ Afternoons ☐ Evenings ☐
- r) Weekdays ☐ Weekends ☐

26. Do you have any other comments that you would like to make about any of the areas covered in this booklet?

THANK YOU VERY MUCH FOR YOUR HELP.

**Please return this questionnaire
in the FREEPOST envelope provided.**

*If this questionnaire has raised any issues which are of concern to you please
do not hesitate to contact:*

*Mrs Joyce Campbell (Genetic Research Nurse)
Tel: 0131 651 1805*

**PROFESSIONAL EVALUATION OF A PSYCHOEDUCATIONAL INFORMATION
PACK FOR WOMEN AT INCREASED RISK OF BREAST CANCER**

Topic :

1. Content (including text, any diagrams and published leaflets):

a) Please rate the extent to which the topic covered all relevant information?

Poor	Adequate	Good	Very Good
1	2	3	4

b) Do you think there was any relevant information *missing* from the topic?

Yes ☐ No ☐

If so, which information?

c) Do you think there was any information *included* in the topic that was not relevant?

Yes ☐ No ☐

If so, which information?

2. Clarity:

a) Please rate the clarity of the topic?

Poor	Adequate	Good	Very Good
1	2	3	4

3. *Presentation:*

a) Please rate the presentation of the topic?

Poor

Adequate

Good

Very Good

1

2

3

4

4. *Overall Quality:*

a) Please rate the overall quality of the topic?

Poor

Adequate

Good

Very Good

1

2

3

4

5. *Additional comments & suggestions:*

We would welcome any further comments or suggestions on this topic or the information pack in general (either write them here or on the topic sheets themselves)

THANK YOU VERY MUCH FOR YOUR HELP

Telephone Feedback on Draft Information Pack from Pilot Sample

Check that the participant has got the information pack in front of them.

1. How much of the information pack did you read?

		All	Some	None
1	Introduction to Breast Cancer			
2	Breast Cancer Genetics <i>Cancer genetics leaflet</i>			
3	Genetic Testing			
4	Ways to Manage Breast Cancer Risk <i>Breast awareness booklet</i>			
5	Breast Cancer Treatment			
6	Hormone Replacement Therapy			
7	Research at the Ardmillan Clinic			
8	Healthy Lifestyle			
9	Worry about Breast Cancer <i>How to... stop worrying booklet</i>			
10	Sources of Information			

2. To what extent do you think the information pack covered the right amount of information?

Too little Too much
0 1 2 3 4 5 6 7 8 9 10

Which info missing?

Which info not relevant?

3. To what extent you do think the information pack contained the right amount of detail?

Not enough detail Too much detail
0 1 2 3 4 5 6 7 8 9 10

Which topics not enough detail?.....

Which topics too much detail?.....

4. Do you think the printed leaflets included in the back of the pack were a useful addition?

Cancer genetics.....

Breast awareness.....

How to...stop worrying.....

5. To what extent did you find the information pack easy to understand?

Very easy to understandVery difficult to understand

0 1 2 3 4 5 6 7 8 9 10

Which topics difficult to understand?.....

Genetics diagrams easy to understand/helpful?.....

6. To what extent was the information in the pack new to you?

None newAll new

0 1 2 3 4 5 6 7 8 9 10

Which topics new?.....

7. To what extent did you find the information in the pack upsetting?

None upsettingAll upsetting

0 1 2 3 4 5 6 7 8 9 10

Which topics upsetting?.....

8. To what extent was the information pack easy to use?

Very easyVery difficult

0 1 2 3 4 5 6 7 8 9 10

Why difficult?.....

9. Please could you rate the overall helpfulness of the information pack?

Not at all helpful

012345678910

Very helpful

Why not helpful?.....

Any additional comments/suggested improvements:

Thank you for your help.

Please could I ask you to keep this information pack confidential at the moment. In the next few weeks we will be starting a new study to evaluate the usefulness of the information pack. We will be comparing a group of women who are sent the information pack and a group who are not sent it. When this study is completed during the summer, we will send you a copy of the final information pack, which you can then use as you like.

Providing Information for Long-term Attendees of the Ardmillan Clinic

QUESTIONNAIRE

ID Number:

PRIVATE AND CONFIDENTIAL

This booklet should take approximately 20 minutes to complete.

Please don't think for too long about each of your answers but give your immediate response. Please try to answer all of the questions.

Please note, the questions are printed on both sides of the page.

If you have any queries about the study or the questionnaire booklet, do not hesitate to contact Sally Appleton on the telephone number below.

When you have finished, please return the booklet as soon as possible in the FREEPOST envelope provided.

THANK YOU VERY MUCH FOR YOUR HELP

For the attention of:

Sally Appleton, Imperial Cancer Research Fund, Postgraduate Psychologist, Department of Clinical Psychology, Outpatient Building, Western General Hospital, Edinburgh EH4 2XU
Tel: 0131 537 1838 E-mail: S.Appleton@icrf.icnet.uk

Please fill in today's date: (day/month/year) __/__/2001

Please fill in your Date of Birth: (day/month/year) __/__/____

We want to learn what people understand about their risk of developing breast cancer.

1. Do you think that your risk of ever developing breast cancer is:
(please tick the appropriate box)

- a. Lower than the general population ☐
- b. The same as the general population ☐
- c. Slightly higher than the general population ☐
- d. Much higher than the general population ☐

2. How likely do you feel it is that you will ever develop breast cancer?
(please circle the appropriate number)

- | | | | | |
|------------------|----------|--------|----------------|------------|
| Very
Unlikely | Unlikely | Likely | Very
likely | Inevitable |
| 1 | 2 | 3 | 4 | 5 |

3. How much control do you feel you have over whether you ever develop breast cancer?
(please circle the appropriate number)

- | | | | |
|----------------|-------|----------|-------|
| None
at all | A bit | Moderate | A lot |
| 1 | 2 | 3 | 4 |

4. It would be helpful if you could give us the following information by ticking the appropriate box.

a) Have you attended the Ardmillan Familial Breast Cancer Clinic in the last 2 weeks?

Yes ☐ No ☐

b) Do you have an appointment at the Ardmillan Familial Breast Cancer Clinic in the next 2 weeks?

Yes ☐ No ☐

c) Are you currently waiting for the results of a mammogram or breast biopsy?

Yes ☐ No ☐

5. We are interested in what people feel they do and do not understand about the issues surrounding familial breast cancer. Please answer **all** of the following questions by ticking the appropriate box. Please don't think for too long about each of your answers. We are interested in your immediate response to each question.

a) The **main** cause of **all** breast cancer is:

	TRUE	FALSE	DON'T KNOW
1. a build up of genetic mistakes in breast cells	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. inherited genetic susceptibility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

b) **Most** women diagnosed with breast cancer:

	TRUE	FALSE	DON'T KNOW
1. have a family history of breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. carry an inherited genetic mistake	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. are diagnosed at age 50 or over	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

c) An increased risk of breast cancer can be passed down through families:

	TRUE	FALSE	DON'T KNOW
1. only by women with breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. only by people who have inherited a genetic mistake	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. by men	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

d) Genetic testing:

	TRUE	FALSE	DON'T KNOW
1. can tell if a person will develop breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. can find mistakes in all the genes that cause an inherited genetic susceptibility to breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. can only be offered if a mistake in the genes BRCA1 or BRCA2 has been identified in the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

e) If a person has inherited a mistake in the genes BRCA1 or BRCA2:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. they will definitely develop breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. their risk of developing breast cancer is increased | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. they are more likely to develop breast cancer at a younger age | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

f) **The children** of a person who has inherited a mistake in the genes BRCA1 or BRCA2:

- | | TRUE | FALSE | DON'T KNOW |
|--|--------------------------|--------------------------|--------------------------|
| 1. will definitely inherit the genetic mistake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. have a 50% chance of inheriting the genetic mistake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. can only inherit the genetic mistake if they are the same sex as their parent who has inherited the genetic mistake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

g) The following are designed to **reduce the risk** of breast cancer developing:

- | | TRUE | FALSE | DON'T KNOW |
|--------------------------------|--------------------------|--------------------------|--------------------------|
| 1. mammography | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. clinical breast-examination | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. breast awareness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. prophylactic surgery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. tamoxifen | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

h) Mammography:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. can prevent breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. is proven to be useful for women under 50 with a family history of breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. aims to detect breast cancer at an early stage when it is easier to treat | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

i) In the National Breast Screening Programme:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. mammograms are only offered to women aged 50-64 years | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. women aged 65 and over can request mammograms | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. mammograms are offered every 3 years | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. women with a significantly increased risk of breast cancer cannot continue to have mammograms more frequently than every 3 years | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

j) For women in the general population the risk of breast cancer:

- | | TRUE | FALSE | DON'T KNOW |
|--|--------------------------|--------------------------|--------------------------|
| 1. increases after one year of using Hormone Replacement Therapy (HRT) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. increases after five years of using HRT | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. returns to normal levels 1 year after stopping HRT | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. returns to normal levels 5 years after stopping HRT | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

k) For women with a family history of breast cancer:

- | | TRUE | FALSE | DON'T KNOW |
|--|--------------------------|--------------------------|--------------------------|
| 1. the effect of using HRT on the risk of breast cancer is not clear | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. MRI breast screening is widely available | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Tamoxifen is widely available | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

6. *We are interested to know if you have had any medical complaints, and how your health has been in general over the past few weeks. Please answer ALL the questions on the following pages simply by circling the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.*

It is important that you try to answer ALL the questions. Thank you very much for your co-operation.

HAVE YOU RECENTLY

been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less than usual
felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

7. The following questions ask about any concerns you may have regarding breast cancer. For each question please tick one box to indicate your answer.

- a. During the past month, how often have you thought about your own chances of developing cancer? Would you say..... (Please tick one box to indicate your answer)

Not at all or rarely
Sometimes
Often
Almost all of the time

- b. During the past month, have thoughts about your chances of getting cancer affected your mood? Would you say.....

Not at all or rarely
Sometimes
Often
Almost all of the time

- c. During the past month, have thoughts about your chances of getting cancer affected your ability to perform your daily activities? Would you say.....

Not at all or rarely
Sometimes
Often
Almost all of the time

- d. How concerned are you about the possibility that you might get cancer someday? Would you say.....

Not at all
Somewhat
Moderately
Very concerned

- e. How often do you worry about developing cancer? Would you say.....

Not at all
Occasionally
Frequently
Constantly

- f. How much of a problem is worrying about cancer to you? Would you say.....

Not at all
Somewhat
Definitely
Severe problem

8. We are interested in how people think about their risk of breast cancer. Please circle the appropriate number to indicate how frequently these comments were true for you **during the past week**.

If you have not thought about your risk of breast cancer **in the past week**, please tick this box and go on to the next page.

I have not thought about the risk of breast cancer ☐
 (If you have ticked this box, go on to the next page)

		Not at all	Rarely	Sometimes	Often
a.	I thought about it when I didn't mean to	1	2	3	4
b.	I avoided letting myself get upset when I thought about it or was reminded of it	1	2	3	4
c.	I tried to remove it from memory	1	2	3	4
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind	1	2	3	4
e.	I had strong waves of feelings about it	1	2	3	4
f.	I had dreams about it	1	2	3	4
g.	I stayed away from reminders of it	1	2	3	4
h.	I felt as if it wasn't real	1	2	3	4
i.	I tried not to talk about it	1	2	3	4
j.	Pictures about it popped into my mind	1	2	3	4
k.	Other things keep making me think about it	1	2	3	4
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	1	2	3	4
m.	I tried not to think about it	1	2	3	4
n.	Any reminder brought back feelings about it	1	2	3	4
o.	My feelings about it were sort of numb	1	2	3	4

9. Do you have any other comments that you would like to make about any of the areas covered in this questionnaire?

THANK YOU VERY MUCH FOR YOUR HELP.

**Please return this questionnaire
in the FREEPOST envelope provided.**

Providing Information for Long-term Attendees of the Ardmillan Clinic

QUESTIONNAIRE

ID Number:

PRIVATE AND CONFIDENTIAL

This booklet should take approximately 30 minutes to complete.

Please don't think for too long about each of your answers but give your immediate response. Please try to answer all of the questions.

Please note, the questions are printed on both sides of the page.

If you have any queries about the study or the questionnaire booklet, do not hesitate to contact Sally Appleton on the telephone number below.

When you have finished, please return the booklet as soon as possible in the FREEPOST envelope provided.

THANK YOU VERY MUCH FOR YOUR HELP

For the attention of:

Sally Appleton, Imperial Cancer Research Fund, Postgraduate Psychologist, Department of Clinical
Psychology, Outpatient Building, Western General Hospital, Edinburgh EH4 2XU
Tel: 0131 537 1838 E-mail: S.Appleton@icrf.icnet.uk

Please fill in today's date: (day/month/year) __/__/2001

Please fill in your Date of Birth: (day/month/year) __/__/____

We want to learn what people understand about their risk of developing breast cancer.

1. Do you think that your risk of ever developing breast cancer is:

(please tick the appropriate box)

- | | | |
|----|---|--------------------------|
| a. | Lower than the general population | <input type="checkbox"/> |
| b. | The same as the general population | <input type="checkbox"/> |
| c. | Slightly higher than the general population | <input type="checkbox"/> |
| d. | Much higher than the general population | <input type="checkbox"/> |

2. How likely do you feel it is that you will ever develop breast cancer?

(please circle the appropriate number)

- | | | | | |
|------------------|----------|--------|----------------|------------|
| Very
Unlikely | Unlikely | Likely | Very
likely | Inevitable |
| 1 | 2 | 3 | 4 | 5 |

3. How much control do you feel you have over whether you ever develop breast cancer?

(please circle the appropriate number)

- | | | | |
|----------------|-------|----------|-------|
| None
at all | A bit | Moderate | A lot |
| 1 | 2 | 3 | 4 |

4. *It would be helpful if you could give us the following information by ticking the appropriate box.*

a) Have you attended the Ardmillan Familial Breast Cancer Clinic in the last 2 weeks?

Yes ☐ No ☐

b) Do you have an appointment at the Ardmillan Familial Breast Cancer Clinic in the next 2 weeks?

Yes ☐ No ☐

c) Are you currently waiting for the results of a mammogram or breast biopsy?

Yes ☐ No ☐

5. We are interested in what people feel they do and do not understand about the issues surrounding familial breast cancer. Please answer **all** of the following questions by ticking the appropriate box and **without referring back to the information pack**. Please don't think for too long about each of your answers. We are interested in your immediate response to each question.

a) The **main** cause of **all** breast cancer is:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. a build up of genetic mistakes in breast cells | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. inherited genetic susceptibility | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

b) **Most** women diagnosed with breast cancer:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. have a family history of breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. carry an inherited genetic mistake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. are diagnosed at age 50 or over | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

c) An increased risk of breast cancer can be passed down through families:

- | | TRUE | FALSE | DON'T KNOW |
|--|--------------------------|--------------------------|--------------------------|
| 1. only by women with breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. only by people who have inherited a genetic mistake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. by men | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

d) Genetic testing:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. can tell if a person will develop breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. can find mistakes in all the genes that cause an inherited genetic susceptibility to breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. can only be offered if a mistake in the genes BRCA1 or BRCA2 has been identified in the family | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

e) If a person has inherited a mistake in the genes BRCA1 or BRCA2:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. they will definitely develop breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. their risk of developing breast cancer is increased | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. they are more likely to develop breast cancer at a younger age | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

f) **The children** of a person who has inherited a mistake in the genes BRCA1 or BRCA2:

- | | TRUE | FALSE | DON'T KNOW |
|--|--------------------------|--------------------------|--------------------------|
| 1. will definitely inherit the genetic mistake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. have a 50% chance of inheriting the genetic mistake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. can only inherit the genetic mistake if they are the same sex as their parent who has inherited the genetic mistake | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

g) The following are designed to **reduce the risk** of breast cancer developing:

- | | TRUE | FALSE | DON'T KNOW |
|--------------------------------|--------------------------|--------------------------|--------------------------|
| 1. mammography | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. clinical breast-examination | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. breast awareness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. prophylactic surgery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. tamoxifen | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

h) Mammography:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. can prevent breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. is proven to be useful for women under 50 with a family history of breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. aims to detect breast cancer at an early stage when it is easier to treat | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

i) In the National Breast Screening Programme:

- | | TRUE | FALSE | DON'T KNOW |
|---|--------------------------|--------------------------|--------------------------|
| 1. mammograms are only offered to women aged 50-64 years | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. women aged 65 and over can request mammograms | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. mammograms are offered every 3 years | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. women with a significantly increased risk of breast cancer cannot continue to have mammograms more frequently than every 3 years | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

j) For women in the general population the risk of breast cancer:

- | | TRUE | FALSE | DON'T KNOW |
|--|--------------------------|--------------------------|--------------------------|
| 1. increases after one year of using Hormone Replacement Therapy (HRT) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. increases after five years of using HRT | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. returns to normal levels 1 year after stopping HRT | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. returns to normal levels 5 years after stopping HRT | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

k) For women with a family history of breast cancer:

- | | TRUE | FALSE | DON'T KNOW |
|--|--------------------------|--------------------------|--------------------------|
| 1. the effect of using HRT on the risk of breast cancer is not clear | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. MRI breast screening is widely available | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Tamoxifen is widely available | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

6. *We are interested to know if you have had any medical complaints, and how your health has been in general over the past few weeks. Please answer ALL the questions on the following pages simply by circling the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.*

It is important that you try to answer ALL the questions. Thank you very much for your co-operation.

HAVE YOU RECENTLY

been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less than usual
felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

7. The following questions ask about any concerns you may have regarding breast cancer. For each question please tick one box to indicate your answer.

a. During the past month, how often have you thought about your own chances of developing cancer? Would you say..... (Please tick one box to indicate your answer)

Not at all or rarely	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Often	<input type="checkbox"/>
Almost all of the time	<input type="checkbox"/>

b. During the past month, have thoughts about your chances of getting cancer affected your mood? Would you say.....

Not at all or rarely	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Often	<input type="checkbox"/>
Almost all of the time	<input type="checkbox"/>

c. During the past month, have thoughts about your chances of getting cancer affected your ability to perform your daily activities? Would you say.....

Not at all or rarely	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Often	<input type="checkbox"/>
Almost all of the time	<input type="checkbox"/>

d. How concerned are you about the possibility that you might get cancer someday? Would you say.....

Not at all	<input type="checkbox"/>
Somewhat	<input type="checkbox"/>
Moderately	<input type="checkbox"/>
Very concerned	<input type="checkbox"/>

e. How often do you worry about developing cancer? Would you say.....

Not at all	<input type="checkbox"/>
Occasionally	<input type="checkbox"/>
Frequently	<input type="checkbox"/>
Constantly	<input type="checkbox"/>

f. How much of a problem is worrying about cancer to you? Would you say.....

Not at all	<input type="checkbox"/>
Somewhat	<input type="checkbox"/>
Definitely	<input type="checkbox"/>
Severe problem	<input type="checkbox"/>

8. *The following questions ask about any changes you may have experienced in your level of worry about breast cancer in the past month.*

DURING THE PAST MONTH...

- a. Do you think that your level of worry about cancer has:
(please circle the appropriate number)

Decreased a lot	Decreased moderately	Decreased a bit	Stayed the same	Increased a bit	Increased moderately	Increased a lot
1	2	3	4	5	6	7

- b. If you think that your level of worry about cancer **has changed** in the past month, **what** do you think may have caused this change?

.....

.....

.....

.....

.....

.....

9. Did you answer questions 7 & 8 (on this page and the previous page) **in relation to worry about...** (please tick one box)

1. breast cancer only ?

2. breast cancer & other cancers ?

<input type="checkbox"/>
<input type="checkbox"/>

(please specify other cancers:
.....)

10. We are interested in how people think about their risk of breast cancer. Please circle the appropriate number to indicate how frequently these comments were true for you **during the past week**.

If you have not thought about your risk of breast cancer **in the past week**, please tick this box and go on to the next page.

I have not thought about the risk of breast cancer
(If you have ticked this box, go on to the next page)

☐

		Not at all	Rarely	Sometimes	Often
a.	I thought about it when I didn't mean to	1	2	3	4
b.	I avoided letting myself get upset when I thought about it or was reminded of it	1	2	3	4
c.	I tried to remove it from memory	1	2	3	4
d.	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind	1	2	3	4
e.	I had strong waves of feelings about it	1	2	3	4
f.	I had dreams about it	1	2	3	4
g.	I stayed away from reminders of it	1	2	3	4
h.	I felt as if it wasn't real	1	2	3	4
i.	I tried not to talk about it	1	2	3	4
j.	Pictures about it popped into my mind	1	2	3	4
k.	Other things keep making me think about it	1	2	3	4
l.	I was aware that I still had a lot of feelings about it, but I didn't deal with them	1	2	3	4
m.	I tried not to think about it	1	2	3	4
n.	Any reminder brought back feelings about it	1	2	3	4
o.	My feelings about it were sort of numb	1	2	3	4

We would like to find out what you think about the information pack you received.

11. How many times have you read each topic in the information pack?
(please circle the appropriate number for each topic)

Topic	None	Once	Twice	More than twice
1. Introduction to Breast Cancer	0	1	2	3
2. Breast Cancer Genetics	0	1	2	3
3. Genetic Testing	0	1	2	3
4. Options for Women with a Family History of Breast Cancer	0	1	2	3
5. Hormone Replacement Therapy	0	1	2	3
6. Diagnosis and Treatment of Breast Cancer	0	1	2	3
7. Research at the Ardmillan Familial Breast Cancer Clinic	0	1	2	3
8. Healthy Lifestyle	0	1	2	3
9. Worry about Breast Cancer	0	1	2	3
10. Sources of Information	0	1	2	3

12. How many times have you read each of the printed leaflets that were included at the back of the information pack?
(please circle the appropriate number for each leaflet)

Leaflet	None	Once	Twice	More than twice
1. "Cancer Genetics"	0	1	2	3
2. "Breast Awareness"	0	1	2	3
3. "How to...Stop Worrying"	0	1	2	3

13. When was the last time you read any of the information pack?

- | | |
|--------------------------|--------------------------|
| 1. In the past week | <input type="checkbox"/> |
| 2. 1-2 weeks ago | <input type="checkbox"/> |
| 3. More than 2 weeks ago | <input type="checkbox"/> |

14. To what extent was the information included in each topic in the pack **new** to you?
(please circle the appropriate number for each topic)

Topic	None New	A little New	Most New	All New
1. Introduction to Breast Cancer	0	1	2	3
2. Breast Cancer Genetics	0	1	2	3
3. Genetic Testing	0	1	2	3
4. Options for Women with a Family History of Breast Cancer	0	1	2	3
5. Hormone Replacement Therapy	0	1	2	3
6. Diagnosis and Treatment of Breast Cancer	0	1	2	3
7. Research at the Ardmillan Familial Breast Cancer Clinic	0	1	2	3
8. Healthy Lifestyle	0	1	2	3
9. Worry about Breast Cancer	0	1	2	3
10. Sources of Information	0	1	2	3

15. Have you discussed the information in your pack with anyone else?

Yes ☐

No ☐

If so with whom? _____

16. Has anyone else read the information in your pack?

Yes ☐

No ☐

If so who? _____

17. Did you find any of the topics of information difficult to understand?

Yes ☐

No ☐

If you answered **Yes**, please *tick* which topics of information you found difficult to understand:

Topic	
1. Introduction to Breast Cancer	
2. Breast Cancer Genetics	
3. Genetic Testing	
4. Options for Women with a Family History of Breast Cancer	
5. Hormone Replacement Therapy	
6. Diagnosis and Treatment of Breast Cancer	
7. Research at the Ardmillan Familial Breast Cancer Clinic	
8. Healthy Lifestyle	
9. Worry about Breast Cancer	
10. Sources of Information	

18. Did you find any of the topics of information upsetting?

Yes ☐

No ☐

If you answered **Yes**, please *tick* which topics of information you found upsetting:

Topic	
1. Introduction to Breast Cancer	
2. Breast Cancer Genetics	
3. Genetic Testing	
4. Options for Women with a Family History of Breast Cancer	
5. Hormone Replacement Therapy	
6. Diagnosis and Treatment of Breast Cancer	
7. Research at the Ardmillan Familial Breast Cancer Clinic	
8. Healthy Lifestyle	
9. Worry about Breast Cancer	
10. Sources of Information	

19. How **helpful did you find each topic of information?**

(please circle the appropriate number for each topic)

Topic	Not at all Helpful	A little Helpful	Quite a bit Helpful	Very much Helpful
1. Introduction to Breast Cancer	0	1	2	3
2. Breast Cancer Genetics	0	1	2	3
3. Genetic Testing	0	1	2	3
4. Options for Women with a Family History of Breast Cancer	0	1	2	3
5. Hormone Replacement Therapy	0	1	2	3
6. Diagnosis and Treatment of Breast Cancer	0	1	2	3
7. Research at the Ardmillan Familial Breast Cancer Clinic	0	1	2	3
8. Healthy Lifestyle	0	1	2	3
9. Worry about Breast Cancer	0	1	2	3
10. Sources of Information	0	1	2	3

20. How **helpful did you find each of the printed leaflets that were included at the back of the information pack?**

(please circle the appropriate number for each leaflet)

Leaflet	Not at all Helpful	A little Helpful	Quite a bit Helpful	Very much Helpful
1. "Cancer Genetics"	0	1	2	3
2. "Breast Awareness"	0	1	2	3
3. "How to...Stop Worrying"	0	1	2	3

21. Which of the following statements corresponds most closely with your response to the information in this pack about:

(please tick the **one** response for each question that is closest to your situation)

a) Being Breast Aware:

1. Since reading the information pack, I **have** become more breast aware. ☐
2. Since reading the information pack, I **intend** to become more breast aware. ☐
3. I was **already** being breast aware. ☐
4. In spite of reading the information pack, I **don't intend** to become more breast aware. ☐

b) Having a Healthier Lifestyle:

1. Since reading the information pack, I **have** adopted a healthier lifestyle. ☐
2. Since reading the information pack, I **intend** to adopt a healthier lifestyle. ☐
3. I was **already** adopting a healthy lifestyle. ☐
4. In spite of reading the information pack, I **don't intend** to adopt a healthier lifestyle. ☐

bi) If you ticked 1 or 2 in response to the last question (i.e. you have adopted or intend to adopt a healthier lifestyle), please tick the appropriate boxes to show which aspects you have changed or intend to change?

1	Healthier diet	<input type="checkbox"/>
2	Stop smoking	<input type="checkbox"/>
3	Reduce alcohol intake	<input type="checkbox"/>
4	Increase skin protection from sun	<input type="checkbox"/>
5	Increase exercise	<input type="checkbox"/>
6	Other (please specify:.....)	<input type="checkbox"/>

c) Ways to Relieve Worries about Breast Cancer:

1. Since reading the information pack, I **have** been using the techniques to relieve worry about breast cancer. ☐
2. Since reading the information pack, I **intend** to use the techniques to relieve worry about breast cancer. ☐
3. I was **already** using techniques to relieve worry about breast cancer. ☐
4. In spite of reading the information pack, I **don't intend** to use the techniques to relieve worry about breast cancer. ☐

22. Do you think you will obtain any of the further reading listed in the information pack?

Yes ☐

No ☐

If so which topic(s)? _____

23. Do you think there was any information **not included** in the pack that you would have liked to know?

Yes ☐

No ☐

If so which topic(s)? _____

24. Do you think the information pack covers your need for information and support?

Yes ☐

No ☐

If you answered **No** what other type of service do you think would be helpful?

25. Do you have any other comments that you would like to make about the information pack or any of the areas covered in this questionnaire?

THANK YOU VERY MUCH FOR YOUR HELP.

**Please return this questionnaire
in the FREEPOST envelope provided.**

Objective knowledge of breast cancer risk-related topics: results for individual items for the intervention study total sample at baseline

Question		N	Correct	Incorrect	Don't Know
The <u>main</u> cause of all breast cancer is:	a build up of genetic mistakes in breast cells? <i>T</i>	155	61 (39%)	27 (17%)	67 (43%)
	inherited genetic susceptibility? <i>F</i>	161	34 (21%)	105 (65%)	22 (14%)
<u>Most</u> women diagnosed with breast cancer:	have a family history of breast cancer? <i>F</i>	162	72 (44%)	73 (45%)	17 (11%)
	carry an inherited genetic mistake? <i>F</i>	159	53 (33%)	60 (38%)	46 (29%)
	are diagnosed at age 50 or over? <i>T</i>	160	72 (45%)	71 (44%)	17 (11%)
An increased risk of breast cancer can be passed down through families:	only by women with breast cancer? <i>F</i>	161	95 (59%)	42 (26%)	24 (15%)
	only by people who have inherited a genetic mistake? <i>T</i>	162	88 (54%)	27 (17%)	47 (29%)
	by men? <i>T</i>	158	52 (33%)	47 (30%)	59 (37%)
Genetic testing:	can tell if a person will develop breast cancer? <i>F</i>	161	65 (40%)	66 (41%)	30 (19%)
	can find mistakes in all the genes that cause an inherited genetic susceptibility to breast cancer ? <i>F</i>	162	41 (25%)	66 (41%)	55 (34%)
	can only be offered if a mistake in the genes BRCA1 or BRCA2 has been identified in the family? <i>T</i>	161	67 (42%)	17 (11%)	77 (48%)
If a person has inherited a mistake in the genes BRCA1 or BRCA2:	they will definitely develop breast cancer? <i>F</i>	163	68 (42%)	10 (6%)	85 (52%)
	their risk of developing breast cancer is increased? <i>T</i>	163	118 (72%)	1 (1%)	44 (27%)
	they are more likely to develop breast cancer at a younger age? <i>T</i>	163	73 (45%)	11 (7%)	79 (49%)
<u>The children</u> of a person who has inherited a mistake in the genes BRCA1 or BRCA2:	will definitely inherit the genetic mistake? <i>F</i>	161	83 (52%)	5 (3%)	73 (45%)
	have a 50% chance of inheriting the genetic mistake? <i>T</i>	162	84 (52%)	10 (6%)	68 (42%)
	can only inherit the genetic mistake if they are the same sex as their parent who has inherited the genetic mistake? <i>F</i>	162	65 (40%)	13 (8%)	84 (52%)

The following are designed to reduce the risk of breast cancer developing:	mammography? <i>F</i>	163	52 (32%)	111 (68%)	0
	clinical breast-examination? <i>F</i>	162	45 (28%)	117 (72%)	0
	breast awareness? <i>F</i>	161	41 (26%)	119 (74%)	1 (1%)
	prophylactic surgery? <i>T</i>	161	67 (42%)	27 (17%)	67 (42%)
	Tamoxifen? <i>T</i>	162	103 (64%)	19 (12%)	40 (25%)
Mammography:	can prevent breast cancer? <i>F</i>	163	147 (90%)	14 (9%)	2 (1%)
	is proven to be useful for women under 50 with a family history of breast cancer? <i>F</i>	163	11 (7%)	135 (83%)	17 (10%)
	aims to detect breast cancer at an early stage when it is easier to treat? <i>T</i>	163	161 (99%)	0	2 (1%)
In the National Breast Screening Programme:	mammograms are only offered to women aged 50-64 years? <i>T</i>	162	128 (79%)	29 (18%)	5 (3%)
	women aged 65 and over can request mammograms? <i>T</i>	162	135 (83%)	4 (3%)	23 (14%)
	mammograms are offered every 3 years? <i>T</i>	162	123 (76%)	17 (11%)	22 (14%)
	women with a significantly increased risk of breast cancer cannot continue to have mammograms more frequently than every 3 years? <i>F</i>	162	110 (68%)	24 (15%)	28 (17%)
For women in the general population the risk of breast cancer:	increases after one year of using Hormone Replacement Therapy (HRT)? <i>F</i>	162	31 (19%)	14 (9%)	117 (72%)
	increases after five years of using HRT? <i>T</i>	161	50 (31%)	6 (4%)	105 (65%)
	returns to normal levels 1 year after stopping HRT? <i>F</i>	161	14 (9%)	9 (6%)	138 (86%)
	returns to normal levels 5 years after stopping HRT? <i>T</i>	162	14 (9%)	11 (7%)	137 (85%)
For women with a family history of breast cancer:	the effect of using HRT on the risk of breast cancer is not clear? <i>T</i>	162	75 (46%)	17 (11%)	70 (43%)
	MRI breast screening is widely available? <i>F</i>	162	54 (33%)	43 (27%)	65 (40%)
	Tamoxifen is widely available? <i>F</i>	162	49 (30%)	34 (21%)	79 (49%)

T = the correct answer to the question was True. *F* = the correct answer to the question was False.

Appendix III

Psychoeducational Written Intervention:

Information pack consisting of scientific and psychosocial topics related to familial risk of breast cancer and three published leaflets (Chapters 5 & 6). *

* for the purposes of inclusion as an appendix, the information pack is not presented in its original ring-binder with coloured topic dividers.

FORMATION PACK

**For Women
with a Family History of
Breast Cancer**







Introduction to this Information Pack

The Imperial Cancer Research Fund has funded this information pack, which has been written specifically for women with a family history of breast cancer who have been attending the Ardmillan Familial Breast Cancer Clinic for several years. We have included 10 topics of up-to-date information related to familial risk of breast cancer. In order to decide which topics to include we followed the advice of staff from the Ardmillan clinic and from many women attending the clinic.

You may want to read the whole information pack from cover to cover or you may just want to look at specific topics of information. We have therefore colour-coded the topics and separated them by topic dividers so you can easily find a particular topic. You may find some sections more interesting than others and different topics may be more helpful at different times. As many of the topics are related to each other, we will sometimes refer you to pages in another topic for more information on a specific issue.

At the end of some topics of information you will find a “**Key points**” box which lists the main points of information included in that topic.

Throughout the information pack there are “**Further Information**” boxes. These suggest where you can get more information on a specific topic. A number of different symbols show you if the information is available:

- as a leaflet 
- online (via the Internet) 
- as a book 
- by telephone 

If you would like to obtain the further information we have suggested, turn to the appropriate page in Topic 10 “Sources of information” to get the contact details of the relevant organisation.

For some topics, we have included published leaflets and you can find these in the plastic pockets at the back of the file. There is also room for you to add any other relevant information you collect.

We hope that you find this information pack useful.



Sally Appleton (Postgraduate Psychologist)



Dr Ann Cull (Consultant Clinical Psychologist)

May 2001

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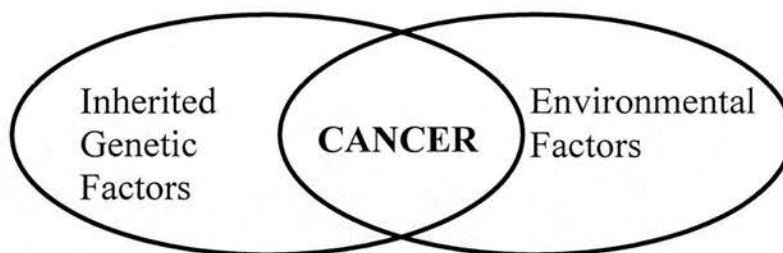
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Topic 1: Introduction to Breast Cancer

What is Cancer?

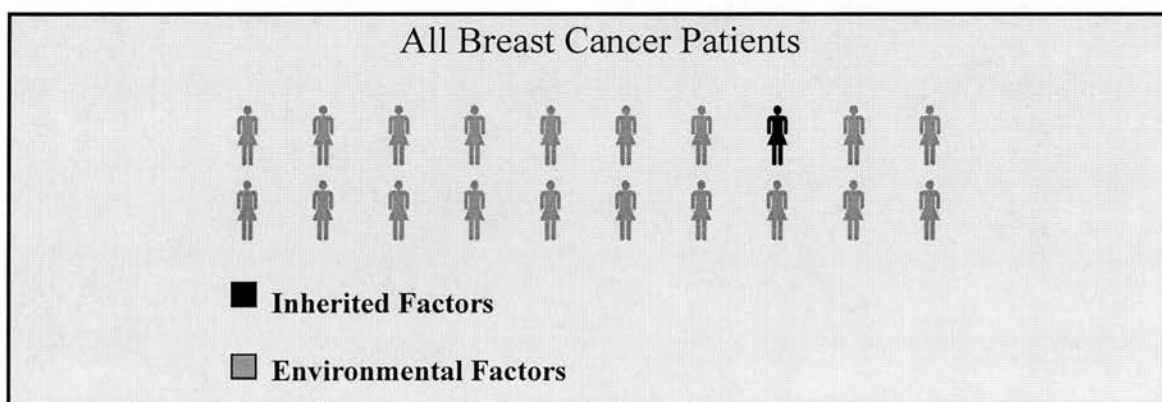
Cancer is a common disease, which can occur in any organ of the body. A cancer is an uncontrollable new growth of cells (often called a “*malignant tumour*”). It results from one cell, which has managed to escape normal cell control. The cell can then divide, invade neighbouring tissue and even spread (“*metastasise*”) to areas further away in the body.

A number of factors are involved in the development of cancer. These can include *hereditary* (“*inherited*”) *genetic* factors and *environmental* factors.



Most cancer, including breast cancer, is sporadic. This means it occurs mainly by chance due to environmental factors.

It is estimated that only 5-10% of all cancers, including breast cancer, are due to hereditary factors (i.e. due to an inherited genetic susceptibility) (see topic 2, page 8).



About Breast Cancer

Breast cancer is a malignant tumour which develops in the cells of the breast. It is the commonest cancer in women in the U.K (excluding non-melanoma skin cancer), accounting for 20% of all new cases of cancer. The average lifetime risk of breast cancer for women in the U.K. is 8%. That means that approximately 1 in 12 of all women in the U.K will develop breast cancer before the age of 74 years. However, at the age of 40-50 years, the risk of developing breast cancer is about 1% (about 1 in 100 women aged 40-50 years will develop breast cancer). This is because a woman's risk of breast cancer continues to increase after the menopause ("*change of life*"). Breast cancer can also occur in men, although it is much more rare (fewer than 1 in 100,000 men in the U.K. will develop breast cancer).

Research has shown that people can inherit a genetic susceptibility to developing breast cancer. This was shown by the fact that:





- Several individuals in the same family often develop breast cancer.
- The risk of breast cancer is increased in relatives of individuals with the disease.

Studies also showed that breast cancer in these families develops at a relatively early age (i.e. in the 30's or 40's), more commonly affects both breasts (*bilateral* breast cancer) and is often associated with cases of ovarian cancer in relatives.

Key Points about Breast Cancer:

- Both inherited and environmental factors are involved in the development of cancer.
- 90-95% of breast cancer is sporadic which means that it is mainly caused by chance due to environmental factors.
- 5-10% of breast cancer is hereditary which means that it is mainly caused by an inherited genetic susceptibility.

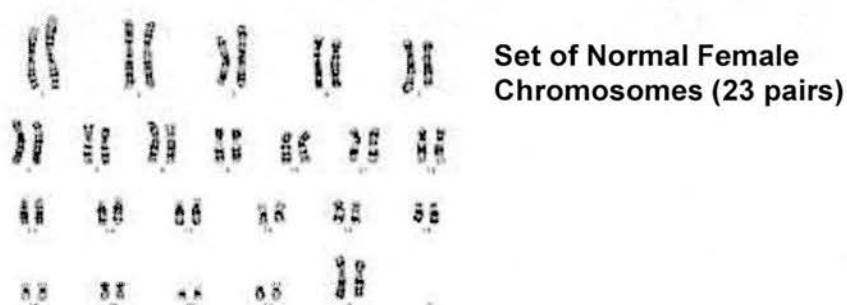
To obtain further information on this topic see:

-  Imperial Cancer Research Fund "Breast Cancer: background", topic 10 page 42.
-  Cancer Research Campaign: Cancer Help UK "About Cancer: cells and cancer", topic 10 page 41.
-   Royal Marsden Hospital "Cancer of the Breast"(in Patient Information), topic 10 page 43.

Topic 2: Breast Cancer Genetics

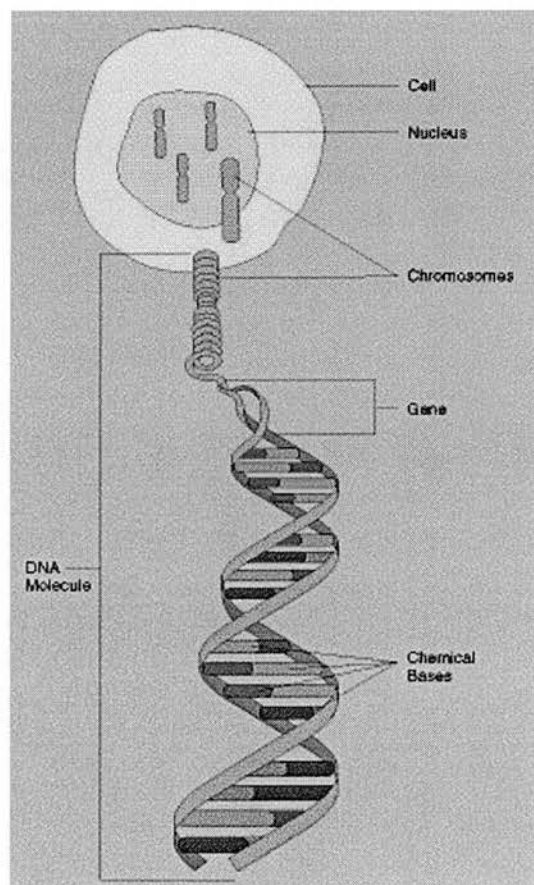
What are Genes?

We are all made up of millions of tiny building blocks called cells. Inside each of these cells we have 23 pairs of *chromosomes* that are actually long strands of *DNA* ("Deoxyribonucleic Acid").



(from <http://www.pathology.washington.edu/Cytogallery/cytogallery.html>)

The DNA in our chromosomes is organised into about 30,000 different *genes*. Genes are responsible for making us what we are. For example, some genes determine eye colour and other genes determine blood group. Each gene is located in a particular place on a particular chromosome.



(from CancerNet "Understanding Gene Testing" booklet)

In some families, breast cancer has partly been caused by a mistake in one particular gene on one particular chromosome. People with an inherited mistake in a specific gene are at increased risk of developing breast cancer. If someone does have a mistake in this gene predisposing them to breast cancer, their children will have a 50% chance of inheriting this mistake. This is because we inherit one of each pair of chromosomes from our mother and the other from our father.

What are Genetic Mutations?

Cells grow and divide to produce identical copies of themselves. Each of the cells produced in turn grows and divides to produce identical copies of itself. Each time cells divide they have to produce identical copies of all their components, including their unique pattern of DNA. This process is very complicated and when a cell is dividing, errors may occur in the genetic code. Things in our environment such as ultra violet light and tobacco smoke are continually causing these errors. These errors can be known as *mutations*. However, control mechanisms usually quickly identify these errors and either correct them or cause the affected cell to die.

How does Cancer normally occur?

All forms of cancer are abnormalities in the normal control of cell growth. Therefore, a cell which loses its normal pattern of growth, can be transformed into a cancer cell. If the control mechanisms are not working properly, a cell, which contains mistakes in its DNA, can be encouraged to grow and divide at a higher rate.

It takes several genetic mistakes for the cell to grow out of control and these mistakes take time to accumulate. This is why sporadic cancer tends to occur in older individuals.

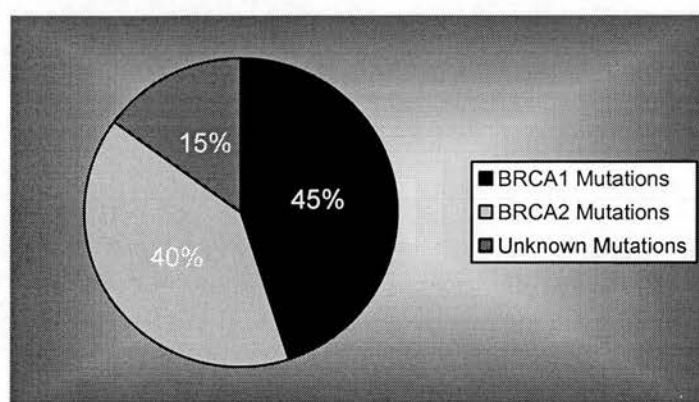
Can Breast Cancer be inherited?

90-95% of cancers are “sporadic” not “inherited” diseases. However, about 5 to 10% of breast cancer is thought to be caused by hereditary factors. This means that although an affected person’s children have not inherited cancer, they may have inherited a susceptibility or predisposition to develop it. This susceptibility can be inherited from either their mother or their father (as we have 2 copies of each gene) and some people inherit a susceptibility to breast cancer without ever developing breast cancer themselves.

If they have inherited this susceptibility, the time span for the cancer to develop may be shortened, as it will not take as long for further genetic mistakes to occur. Often, the same type of cancer tends to develop in more than one family member at a young age. This is because the genetic mutations that are inherited occur in genes which are important to cells in a particular area of the body, such as the breasts.

In the 1990's two genes for breast cancer susceptibility were identified. The genes were called BRCA1 and BRCA2 and they play an important role in the control of cell growth and division. These two genes account for a large proportion of breast cancer in high-risk families (where four or more family members in three generations develop breast cancer). If someone has a mistake in BRCA1 or BRCA2 they have a 50% chance of passing this susceptibility to breast cancer on to each of their children.

It is currently estimated that about 45% of cases of familial breast cancer are due to BRCA1 mutations and a further 40% to BRCA2 mutations (these estimates vary between different cultures and regions). Although there is evidence for at least a third familial breast cancer gene, this has not yet been identified.




There is also evidence for overlap between breast and ovarian cancer susceptibility. BRCA1 mutations account for most families with inherited breast and ovarian cancer susceptibility, particularly where the onset of breast cancer is at 45 years or younger. BRCA2 mutations account for a strong susceptibility to breast cancer and a smaller risk of ovarian cancer than BRCA1 mutations. People who carry a BRCA2 genetic mutation are also predisposed to other cancers.

Key Points on Breast Cancer Genetics:

- Inherited mistakes in the genes BRCA1 or BRCA2 increase a person's risk of developing breast cancer.
- Only 5-10% of breast cancer occurs as a result of inheriting a genetic mistake in BRCA1 or BRCA2.
- The children of a person who carries a mistake in BRCA1 or BRCA2, will each have a 50% chance of inheriting the susceptibility to breast cancer.

To obtain further information on this topic see:

 Genetic Interest Group "An Introduction to Genetics"(in Education), topic 10 page 42.

  CancerNet "Understanding Cancer" (in NCI Publications: Genetics), topic 10 page 41.

Topic 3: Genetic Testing

What is Genetic Testing?

Genetic testing aims to find mistakes in the two genes, BRCA1 and BRCA2, which are known to cause an inherited genetic susceptibility to developing breast cancer. Mistakes can occur at almost any position along a gene. So far, over 200 different mistakes in BRCA1 and about 100 in BRCA2 have been reported. Therefore, trying to find a mistake in one of these genes is very time consuming, technically demanding and expensive. Genetic testing for mistakes in BRCA1 and BRCA2 has only recently been introduced in the U.K.

We have included the South East of Scotland Clinical Genetic Service leaflet on “Cancer Genetics” at the back of this pack for your information. It contains information on genetic testing.

Who should be tested?

In order to offer genetic testing, the laboratory has to be able to identify if there is a genetic mistake being inherited in the family. To do this, they search for a mistake in BRCA1 or BRCA2 using a sample of blood from a family member with breast or ovarian cancer. If a mistake is identified, the healthy relatives that may be at risk can then be offered a blood test to determine if they have inherited this specific genetic mistake.

To decide who is eligible for this process, familial breast cancer clinics follow national guidelines (for more information on genetic testing in Scotland see topic 7, page 23).

Women at moderate risk of breast cancer

Most women referred to a familial breast cancer clinic, because of a family history of the disease, are considered after appropriate assessment to be at moderate risk of developing breast cancer (between 2 and 3 times the general population lifetime risk). Women in this group are *not usually eligible* for genetic testing.

Women at high risk of breast cancer

A small number of women referred to a familial breast cancer clinic, because of a strong family history of the disease, are considered to be at high risk of developing breast cancer (greater than 3 times the general population lifetime risk). Women in this group *may be eligible* for genetic testing.

What do genetic test results mean?

A “positive” test result means that the woman is found to carry a genetic mistake in BRCA1 or BRCA2 and has therefore inherited a genetic susceptibility to breast cancer. Some studies have estimated that carriers of BRCA1 or BRCA2 mutations have between a 60-85% risk of developing breast cancer by the age of 70. Therefore, even if you receive a *positive* test result, it does not mean that you will definitely develop breast cancer.







Women who receive *positive* genetic test results are offered appropriate breast cancer screening and information on which to base their choices about ways of trying to reduce the risk of breast cancer developing, such as “*prophylactic mastectomy*” (surgical removal of the breasts) (for further information on prophylactic surgery see topic 4, page 14).

A “negative” test result means that the woman’s risk of breast cancer is reduced to the general population lifetime risk of breast cancer (i.e. 8% in the U.K.), as she is not found to carry the specific genetic mistake identified in her family. Therefore, she is not at sufficiently increased risk to require screening and she is advised to join the NHS Breast Screening Programme when she is 50.

Key Points on Genetic Testing:

- Genetic testing can only be offered to healthy individuals once a genetic mistake in BRCA1 or BRCA2 has been identified in a family member with breast cancer.
- Only a small number of women at high risk of breast cancer are usually eligible for genetic testing.
- A *positive* test result means that a genetic susceptibility to breast cancer has been inherited.
- A *positive* test result does not mean that you will definitely develop breast cancer.
- A *negative* test result reduces breast cancer risk to the general population level.

To obtain further information on this topic see: (the websites/leaflets listed below are from the U.S.A. You need to be aware that genetic testing is more widely available in the U.S.A. Therefore, some information may not be applicable to British women)

-   CancerNet “Understanding Gene Testing” (in Genetics, Causes, Risk Factors, Prevention: Cancer Genetics: General Cancer Genetics Information), topic 10 page 41.
-   CancerNet “Genetic Testing for Breast Cancer Risk: It’s Your Choice” (fact sheet & booklet in Genetics, Causes, Risk Factors, Prevention: Cancer Genetics: Type of Cancer), topic 10 page 41.
-   CancerNet “Understanding Cancer” (in NCI Publications: Genetics), topic 10 page 41.

Topic 4: Options for Women with a Family History of Breast Cancer

Since the actual causes of breast cancer are not completely understood, it is currently not possible to prevent the development of cancer.

However, there are a number of different ways to manage an increased risk of breast cancer which aim to:

- Detect breast cancer at an early stage when it is easier to treat.
- OR*
- Reduce the risk of breast cancer developing.

Screening

Breast cancer screening is considered to be the key way to manage breast cancer risk. Screening does not reduce the risk of cancer, but aims to diagnose it at an early stage so that appropriate treatment can be started to improve the chances of survival. There are several forms of screening that are currently available for detecting breast cancer: *mammography, clinical breast-examination and breast self-examination* (or “breast awareness”). However, there is still uncertainty about the usefulness of screening in women under 50 with a family history of breast cancer. Research trials are also evaluating new forms of screening for women with a family history of breast cancer such as “Magnetic Resonance Imaging”(see topic 7, page 23).

Mammography:

- Mammograms are X-rays of the breast that can often detect cancer before it can be felt. Mammography is currently the best form of breast screening available.
- The National Breast Screening Programme currently offers mammography every three years to all women between the ages of 50-64 who are considered to be at general population risk of developing breast cancer. This is because breast cancer is most common in this age group in the general population. Women aged 65 and over are not automatically invited for screening but they can still request mammograms.
- Research has shown that screening by mammography can reduce the number of deaths from breast cancer in women in the general population by up to 40%. The benefit is greatest in women aged 50 to 70 years, as their breast tissue is generally less dense which allows tumours to be more easily detected.
- In women at increased risk of breast cancer, screening by mammography at a specialist clinic generally begins between the ages of 25-35 (usually from 5 years younger than the age at which their youngest relative was diagnosed with breast cancer). It is generally recommended to be performed every 2 years up to the age of 40 and annually up to the age of 50. Women over 50 are advised to join the National Breast Screening Programme - if they have a significantly increased risk of breast cancer, they are usually offered an extra mammogram between their National Breast Screening Programme mammograms which means they are screened every 18 months.

- The usefulness of mammography in women with a family history of breast cancer aged under 50 is currently unclear. Although the results of recent research have supported the value of mammography in this group of women, this research has used relatively small numbers of women.
- Some women have expressed concern about the possible effect of the radiation from mammograms on their risk of breast cancer. However, the amount of radiation emitted is so small that the benefits of detecting breast cancer early far outweigh the risk of these X-rays causing any harm.

Clinical breast examination (CBE):

- A CBE is a physical examination of the breasts performed by a doctor or nurse.
- Research suggests that CBE can detect cancers that are difficult to identify by mammography. Therefore, CBE is a valuable component of screening in addition to mammography.
- CBE is particularly important for younger women in whom mammography is less sensitive (this is because their breast tissue is generally more dense).
- In women at increased risk of breast cancer, CBE is generally recommended to be performed annually at a specialist clinic and usually beginning at age 35 (or at a younger age if a woman's risk is significantly increased).
- You can also ask your GP to perform a CBE.

Breast Awareness:


- "Breast Awareness" (or "Breast self-examination" as it's sometimes called) means getting to know how your breasts look and feel normally so that you are able to notice any changes that might be unusual for you.


The Breast Awareness 5-point code:

- ❖ Know what is normal *for you*.
- ❖ Know what changes to look and feel for.
- ❖ Look and feel.
- ❖ Report any changes to your GP *without delay*.
- ❖ Attend for routine breast screening if you are aged 50 or over.

- Research to look at the impact of being breast aware on breast cancer survival is so far inconclusive.
- Nevertheless, being breast aware is part of looking after your general health and it is generally recommended that you check your breasts once a month, starting from your early 20's.
- As some cancers can be difficult to detect by mammography, it is important to be breast aware.
- We have included the Breast Cancer Care leaflet "Breast Awareness" at the back of this pack for your information.

To obtain further advice on being breast aware please ask when you next attend the Ardmillan clinic or see:

 NHS Breast Screening Programme & the Cancer Research Campaign “Be Breast Aware”, topic 10 page 43 or 41.

 Imperial Cancer Research Fund “Breast Cancer- Spot the Symptoms Early”, topic 10 page 42.

Prophylactic Surgery

In the U.K., only women at high risk of developing breast cancer are generally offered prophylactic mastectomy (the removal of the breasts before cancer has been diagnosed). Many of these women will have been found to carry a mutation in the genes BRCA1 or BRCA2 (see topic 3, page 11).

Research has shown that prophylactic mastectomy may reduce the risk of developing breast cancer by about 90%. Therefore, it will not definitely prevent the development of breast cancer. This is because all of the breast tissue cannot be removed during prophylactic mastectomy, so there is still a chance that breast cancer could occur.

As prophylactic mastectomy is irreversible, it is extremely important that any woman considering prophylactic mastectomy receives help in understanding the potential risks and benefits (both physical and psychological) of surgery before they come to a final decision. Women who decide to opt for prophylactic mastectomy will be supported before, during and after surgery.

Research also suggests that prophylactic oophorectomy (removal of the ovaries before cancer has been diagnosed) can reduce the risk of developing breast as well as ovarian cancer.

Tamoxifen

Tamoxifen is part of a group of drugs called “Anti-oestrogens”. These drugs are usually used to treat women with advanced breast cancer and are known as “Hormone therapies” (see topic 6, page 20). Tamoxifen works by blocking the effect of the hormone oestrogen, which normally encourages breast cancer cells to grow.

Research with breast cancer patients has shown that Tamoxifen halves the risk of cancer developing in the other breast. In light of these results, research was started to determine whether Tamoxifen could prevent breast cancer developing in women at increased risk of the disease. Studies are currently under way to determine its effectiveness and safety in women at increased risk of breast cancer (see topic 7, page 22). Tamoxifen, however, may cause some side effects such as hot flushes and these tend to be experienced more frequently in women over 50 years.

Research is also currently investigating the effect of other anti-oestrogen drugs such as “Raloxifene” on the prevention of breast cancer in women at increased risk.

These two drugs (Tamoxifen & Raloxifene) are currently not licensed to be used outside of research studies in the U.K.

Key Points on Options for Women with a Family History of Breast Cancer:

- Breast cancer screening includes mammography, clinical breast examination and “breast awareness” and aims to detect breast cancer at an early stage when it is easier to treat.
- The usefulness of breast cancer screening in women with a family history of breast cancer who are under the age of 50 is still unclear.
- Prophylactic surgery and Tamoxifen aim to reduce the risk of breast cancer, although they cannot prevent it developing.

To obtain further information on this topic see:



Imperial Cancer Research Fund “Breast Cancer: symptoms and diagnosis”,
topic 10 page 42.



CancerBACUP “Understanding cancer of the breast: symptoms and diagnosis”,
topic 10 page 41.

Topic 5: Hormone Replacement Therapy (HRT)

What is HRT?

HRT involves replacing the female sex hormones *oestrogen* and *progesterone*. These hormones are produced by the ovaries and are no longer in high levels after the menopause.

The menopause is when a woman's ovaries stop producing eggs each month and menstrual periods stop. A woman is considered to be menopausal when her periods have completely ceased for at least a year and it occurs at an average age of 50.

HRT can help to relieve the symptoms of the menopause such as hot flushes, night sweats and vaginal dryness. It can also improve quality of life, mood and sense of well being as well as helping to reduce the risk osteoporosis (thinning of the bones which can cause bone fractures).

There are two different types of HRT: one contains oestrogen only and the other, more commonly used type, combines oestrogen with progesterone.

HRT & the Risk of Breast Cancer: What does the research show?

As oestrogen is known to promote the growth of some breast cancers, research was needed to see if taking extra oestrogen in the form of HRT could promote the development of breast cancer.

Research in women in the general population has shown that using HRT for more than five years appears to slightly increase a woman's risk of developing breast cancer. The risk increases the longer the time that HRT is used. For every 1,000 women who have been using HRT for 5 years, there would be 2 extra cases of breast cancer diagnosed and for every 1,000 women who have been using HRT for 10 years, there would be 6 extra cases of breast cancer diagnosed. However, the risk of breast cancer returns to normal levels (i.e. the general population risk of breast cancer) five years after stopping treatment.

Mammography is less sensitive in women who are taking HRT, as it increases breast density. However, cancers diagnosed in women taking HRT tend to be less advanced than those diagnosed in women who have not used HRT. Current evidence suggests that HRT does not increase the number of deaths from breast cancer.



Further research is needed to investigate the effect of HRT on the risk of breast cancer, particularly in women with a family history of the disease where the risks are not yet clear. The Imperial Cancer Research Fund is currently involved in "The Million Women Study" which is the world's largest study looking at HRT and the risk of breast cancer. The first results of this study are expected in 2002.

If you are considering HRT, please discuss this with your GP. There are also natural alternatives to HRT which some people find helpful. For more advice, please consult your GP.

Key Points on HRT:

- HRT replaces the hormones *oestrogen* and *progesterone* that are no longer in high levels after the menopause.
- HRT can help to relieve unpleasant symptoms of the menopause, improve quality of life and reduce the risk of osteoporosis.
- Although research has shown that using HRT for more than five years appears to increase a woman's risk of developing breast cancer, it is not clear how these risks relate to women with a family history of breast cancer.

To obtain further information on HRT, please ask your GP, ask when you next attend the Ardmillan clinic or see:

-  Imperial Cancer Research Fund "Breast Cancer: background – risk factors", topic 10 page 42.
-  Cancer Research Campaign: Cancer Help UK "Questions and Answers: causes of cancer", topic 10 page 41.

Topic 6: Diagnosis & Treatment of Breast Cancer

Diagnosis

On occasion, you may be called back to the Ardmillan Clinic for a second visit which might involve further investigations. This could be because, for example, a breast change has been noticed between your last 2 mammograms (this is not necessarily an abnormal change).

Further investigations may include a second mammography, clinical breast examination or *ultrasound* (which uses sound waves to see if a lump is solid or contains fluid). A *tissue biopsy* (where a sample of breast tissue is removed to be examined under a microscope) is the only definite way to tell if a breast lump is benign or malignant (cancerous). There are several different types of biopsy which include *needle aspiration* (when a thin needle is used to remove cells from a breast lump), *needle biopsy* (when a slightly larger needle is used to remove a small piece of tissue from a breast lump) and *surgical biopsy* (where the whole breast lump is removed).

If you are called back to the Ardmillan Clinic for further investigations, it is sometimes possible to give you a definite diagnosis on the same day.

About two thirds of breast abnormalities detected by mammography prove to be benign (not cancerous) on further examination. Benign breast lumps are easily treated and can be caused by *cysts* (which are fluid-filled sacs) or *fibroadenomas* (which are non-cancerous solid tumours).

Introduction to the Treatment of Breast Cancer

Research published in May 2000 has shown that in the last 10 years, the number of deaths from breast cancer in the U.K. has decreased by 30%, which is partly due to improved treatments for breast cancer.

There are a number of different ways of treating breast cancer. These can be divided into 2 main groups:

- *Local* treatments that target the breast.
- *Systemic* treatments that target cancer cells anywhere in the body.

The treatments that are offered to a patient with breast cancer will depend on several factors including their age, the size of the tumour, the *stage* of the cancer (how much it has spread) and *grade* of the cancer (how fast the cancer cells are growing when viewed under a microscope). Women who have been found to carry a mutation in the genes BRCA1 or BRCA2 and subsequently develop breast cancer, may initially receive very intensive treatment. Most patients with breast cancer will have a combination of local and systemic treatments and can have a share in treatment decisions with their cancer specialist if they wish. Full support before, during and after treatment is provided by breast care nurses for both the patient and their family.

Additional information and support is available from the Maggie's Cancer Caring Centre at the Western General Hospital, Edinburgh (see topic 10, page 43).

The prognosis (how likely you are to get better and how long you are likely to live) for a patient with breast cancer depends upon the stage of the cancer when it was diagnosed. Therefore, you are more likely to have a better prognosis if your cancer is diagnosed at an early stage. For example, 85 out of every 100 (85%) women diagnosed with localised breast cancer between 1985-1989 lived for at least 5 years after being diagnosed, compared to 21 out of every 100 (21%) women who were diagnosed with *metastatic* breast cancer (cancer that has spread from the breast).

Local Treatments

Surgery:

- There are several different types of breast cancer surgery. The most common types are *breast conservation surgery* and *mastectomy*.
- Breast conservation surgery includes a *lumpectomy* (where the breast lump is removed with a small amount of surrounding breast tissue) and a *partial mastectomy* or *quadrantectomy* (where up to one quarter of the breast is removed).
- All forms of breast conservation surgery are usually followed by a course of radiotherapy.
- *Mastectomy* removes the whole breast and varying degrees of surrounding chest muscle and lymph glands (which are in the armpit). Most patients treated by mastectomy are offered some form of surgery to reconstruct the breast such as breast implants.
- After any form of surgery, patients usually receive follow-up checks to make sure that breast cancer hasn't recurred or developed in the other breast. This is because all patients with cancer in one breast are at increased risk of developing cancer in the other breast.

Radiotherapy:

- Radiotherapy uses high-energy rays to kill cancer cells.
- All patients who undergo breast conservation surgery and some patients who undergo mastectomy, receive radiotherapy for a few weeks after surgery.
- Radiotherapy can also be given before surgery to reduce the size of a breast lump so that it can be removed more easily.

Systemic Treatments

Chemotherapy:

- Chemotherapy uses anti-cancer drugs to kill cancer cells. As the drugs are carried round the body in the blood they can kill cancer cells anywhere in the body.
- Chemotherapy can be given before surgery to reduce the size of a breast lump, after surgery to reduce the risk of the breast cancer recurring/spreading to another part of the body or to treat metastatic breast cancer.

- Chemotherapy can be given as a tablet or injected and often includes a combination of different drugs.
- Different combinations of drugs can also have different side effects such as tiredness, hair loss, nausea and vomiting. Information on the possible side-effects is given by breast care nurses, in particular a patient's named nurse will provide full support throughout treatment.
- A full course of chemotherapy can take up to 6 months to complete.

Hormone Therapy:

- Hormone therapy prevents the female hormone, *oestrogen*, from working. This hormone, which naturally occurs in the body, affects the growth of some breast cancer cells. Therefore, hormone therapy aims to decrease the level of oestrogen or stop it from working altogether.
- Hormone therapy can be given before surgery to reduce the size of a breast lump, after surgery to reduce the risk of the breast cancer recurring/spreading to another part of the body or to treat metastatic breast cancer.
- Hormone therapy seems to work best in women who have "*oestrogen receptor positive cancers*" (i.e. their cancer cells have molecules on the surface which activate oestrogen which stimulates breast cancer cells to grow).
- There are several different types of hormone therapy, including Tamoxifen which is the commonest (see topic 4, page 14).





New Treatments

There are a number of new ways of treating breast cancer that are currently being tested and could potentially become standard treatments for breast cancer in the future. One study by the Imperial Cancer Research Fund is looking at whether vaccines can effectively treat metastatic breast cancer, by triggering the body's immune system. Another study by the Imperial Cancer Research Fund is investigating a new "*cell suicide gene*" technique in which cancer cells are killed while healthy cells remain intact. Other research is looking to see if new hormone therapies can improve on the performance of Tamoxifen.

Key Points on the Diagnosis & Treatment of Breast Cancer:

- About two thirds of breast changes detected by mammography prove to be non-cancerous on further examination.
- The type of treatment a breast cancer patient will be offered depends on their age, the size of the tumour, the stage and grade of the cancer.
- Patients can have a share in treatment decisions if they wish.
- Local treatments for breast cancer target the breast and include surgery and radiotherapy.
- Systemic treatments for breast cancer target cancer cells anywhere in the body and include chemotherapy and hormone therapy.

To obtain further information on this topic see:

-  Imperial Cancer Research Fund “Breast Cancer: treatment”, topic 10 page 42.
-   CancerBACUP “Understanding cancer of the breast: treatments”, topic 10 page 41.
-  Cancer Research Campaign: Cancer Help UK “Breast Cancer: treating breast cancer”, topic 10 page 41.

Topic 7: Research at the Ardmillan Familial Breast Cancer Clinic

The Ardmillan Familial Breast Cancer Clinic started in Edinburgh in 1992 for women in Southeast Scotland with a family history of breast cancer. It is now funded by Lothian Primary Care Trust and provides cancer risk counselling and breast screening services for over 1,000 women. A large number of women attending this clinic have been involved in various research projects over the years.

Women who meet the specific criteria for a research study are informed about the study and invited to participate. However, there is no pressure placed on anyone to join these studies and if someone agrees to take part, they can withdraw at any time.

We would like to take the opportunity to thank you if you have taken part in any of these studies and to provide you with an overview of some of the past and present research that has been conducted in the clinic.

International Breast Cancer Intervention Study (IBIS)

IBIS is a 5-year study, which is being run by the Imperial Cancer Research Fund and the Cancer Research Campaign. It aims to discover whether the use of Tamoxifen can help to prevent breast cancer in women at increased risk of the disease (see topic 4, page 14).

Women aged 35-70 who have at least twice the general population risk of developing breast cancer due to their family history of the disease, have been taking part in this study.

The study is being run as a double blind placebo controlled trial. This means that neither the participants nor the medical staff know which type of tablet the participants are receiving, Tamoxifen or the placebo (which is an inactive substance).

Taking part in this study requires a big commitment from the women. They take a trial tablet daily for 5 years and attend the clinic for a clinical breast examination every 6 months and a mammogram every 12 or 18 months.

This study is a multi-centre trial with centres in Australia, New Zealand and Europe, including 4 centres in Scotland. The study has now stopped recruiting women as it has reached its target of 7,000 women taking part worldwide. In Edinburgh, 250 women have taken part in the study and of those 7 have already completed their 5 years of participation. It is hoped that the provisional results of the study will be available in 2002.

MRI Breast Screening Study (Magnetic Resonance Imaging)

This study aims to see if “Magnetic Resonance Imaging” (MRI) can detect breast cancer at an earlier stage than current mammography methods in women with an increased risk of breast cancer. MRI uses magnetic waves to create detailed pictures of the breast (whereas mammography uses X-rays).

The criteria for women to participate in the study are very strict. They are aged between 25-49 years and the majority have four 1st or 2nd degree relatives diagnosed with breast cancer under the age of 60. Many of the women participating have received genetic testing and are known to be carrying a genetic mutation that predisposes them to breast cancer (see topic 3, page 10). The women taking part in this study have an annual mammogram, clinical breast-examination and MRI breast scan for up to 5 years.

This is a multi-centre study with 17 different centres taking part all over the U.K. The trial began in Edinburgh in 1998 and has so far recruited 47 women.

Cancer Genetics in the Community

For the last 3 years, over 300 women newly referred for genetic counselling about their family history of breast cancer have been taking part in a study to compare 2 different ways of organising the service.

Half of the women were referred to the clinic in the usual way. If they did not have a family history which suggested an increased risk of breast cancer, they and their GP would receive a letter to explain why an appointment was not necessary. Those women who were at increased risk of breast cancer were seen at the clinic in the usual way.

The other half of the women were referred to a clinic in their community run by a specially trained genetics nurse. She would see everyone referred and refer on to the Ardmillan clinic only those she found to be at sufficiently increased risk. The results of this study, including the women’s reactions to the service they received, are still being analysed and will be used to inform the future service.

Genetic Testing

The Scottish Health Service has now released funds to the Regional Genetics Services in Aberdeen (which serves Edinburgh) and Glasgow to allow them to offer genetic testing for mutations in BRCA1 and BRCA2, the 2 major genes involved in familial breast cancer (for further information on genetic testing for BRCA1 and BRCA2, see topic 3, page 10). The testing will be offered to families with a living member with breast cancer who meet specific high-risk criteria (i.e. families with 4 or more members with breast or ovarian cancer [including male breast cancer] in 3 generations; families with one member with breast and ovarian cancer). The laboratories hope to start genetic testing by the end of 2001. We anticipate that further information will be sent to any eligible women in the near future.

Psychosocial Research

Introduction

When clinics were first set up to provide genetic counselling and breast cancer screening to women with a family history of cancer, there was uncertainty about how useful these clinics would be. It was understood that it would take many years to see whether they would be effective in reducing the number of deaths from breast cancer. There was a particular worry that information about breast cancer risk would cause people distress particularly since we could not prevent breast cancer developing.

Funding from the Imperial Cancer Research Fund enabled a team of psychologists to become involved in the Ardmillan Familial Breast Cancer Clinic. We wanted to monitor the experience of this clinic through the eyes of the women who attended. We are extremely grateful to the women who have completed questionnaires for us over the years. The information they have given us has informed what we do locally and has also helped others to learn from the experience of this clinic.

Study 1: Impact of the clinic on new attendees (Cull *et al.* 1999)

In 1992, we wanted know who would come to the clinic and what they thought their risk was. If they were mistaken about their risk we wanted to know whether the information they were given at the clinic would change their view. We were concerned that the clinic might cause distress to women if they were told that their risk of breast cancer was greater than they previously thought. This study involved nearly 500 women and took several years to complete.

Understanding the risk of developing breast cancer

About half of the women who took part in this first study came to the clinic already having a pretty accurate idea of their risk. However there were quite a lot of women (nearly 40%) who underestimated their risk and a much smaller proportion who greatly overestimated their risk. This was different from the experience in the U.S.A where many of the women studied tended to overestimate their risk. We were able to show that the information given at the clinic in Edinburgh did help most women to develop a more accurate view of their risk. When we asked them about it again a year or more after they had attended the clinic we found they had been able to maintain this more accurate view. We, of course, need to try to learn more about the people who get stuck with an inaccurate view of their risk to try to work out how best to help them.

We did notice that although most people seemed to understand their risk, there were quite a lot of pieces of information about genetics which they didn't understand so well and we tried to address that in study 2 (see page 25).

Did the clinic cause distress?

We were very relieved to find that for most people, attending the clinic did not affect them one way or the other; 30% actually reported lower levels of distress after the clinic than they had before attending. Many people told us they were relieved that the clinic was in existence. However we did notice a small proportion (about 3 in 20 women) who reported higher levels of distress after the clinic than they had before.

This was not, as we feared, related to learning that their risk of breast cancer was greater than they had thought. We did want to try to understand better the reasons for their distress in order to know how best to help. We found these women tended to already be quite distressed before they came to the clinic and our continuing research in this area led us to pay more attention to people's personal experiences of breast cancer in their families (see study 4, page 26).

Study 2: Is videotaped information about breast cancer genetics useful? (Cull *et al.* 1998)

Cancer genetics is a new and rapidly growing field. The information, which can be given to individuals about their own risk, is complicated and can be difficult to understand. We were concerned about whether there was more we could do to help people understand this type of information, particularly at a time when the clinic was getting busier. But we were also anxious to avoid overloading people with information they did not want or need.

We developed a video about familial breast cancer and tried it out on over 100 women in the clinic. Some women received the video before their appointment whereas others didn't see it until afterwards. After the clinic, the women were asked how well they understood a number of issues related to the genetics of breast cancer and they were also asked a number of factual questions. Women who had seen the video before the clinic felt they understood the issues better and got more factual answers right than the women who had only had the information given to them at the clinic. There was no evidence that the video caused distress to those who watched it nor did it put them off coming to the clinic. In fact women who saw the video beforehand reported more satisfaction with the clinic.

We made a second video for the much smaller number of women at high risk of breast cancer, in anticipation of genetic testing becoming available. In fact that took longer to happen than expected and this video proved most useful to those who were weighing up the pros and cons of prophylactic surgery as a way of reducing their risk of developing breast cancer (see topic 4, page 14).

Although the videos proved useful, they were expensive to make and have become out of date quite quickly in this rapidly developing field. We have not continued using videotaped information in the clinic. However, we are continuing to find how to provide the best service possible within the resources we have available such as developing this information pack.

Study 3: Living with an increased risk of breast cancer (Appleton *et al.* 2000)

Up until now, our studies had focused on women who were recently referred to the clinic. We now felt that it was important to find out how women who had been attending the clinic for several years were managing with the knowledge of their increased risk. We wanted to ask them about the effect on their everyday lives, how they were coping and if they had any needs in terms of information or support that were not being met by the existing service.

In 1999, 25 women who had been attending the clinic for at least 2 years took part in telephone discussion groups to talk about these issues. These women gave us a real insight into what it is like to live with an increased risk of breast cancer.

Although some women described themselves as being generally more worried about breast cancer than others, most women described worries about breast cancer being triggered by events in their lives such as receiving a clinic appointment letter or hearing about breast cancer on the news. All of the women expressed a need for up to date information about topics related to familial breast cancer.

In order to confirm and expand on the results of this small study, 249 women who had been attending the clinic for at least 2 years took part in a subsequent questionnaire study.

The results of both of these studies have helped us to develop the information pack which you are now reading.

Study 4: Understanding distress in women at increased risk

Our previous research suggested that people's personal experiences of breast cancer in their families may help to explain why some women were more distressed at the clinic than others. This study aimed to look at the possible link between distress, experiences of cancer in the family and beliefs about breast cancer.

In 1999-2000, we compared the beliefs of 117 women attending the clinic with the beliefs of 100 women in the general population who hadn't experienced breast cancer in their family or friends.

Although, women at increased risk were more distressed about breast cancer than women in the general population, they were also less confused about the disease and believed that breast cancer held greater consequences for the patient and their family. The women who showed higher levels of distress were those women at increased risk who believed breast cancer to have more symptoms, to be of longer duration and to have more consequences. Women who held these particular beliefs about breast cancer tended to have experienced a recent bereavement in their family.

A better understanding of the reasons why some women are distressed gives us a better opportunity to offer the best possible help.

Topic 8: Healthy Lifestyle

Lifestyle & the Risk of Breast Cancer: What does the research show?

Although a large amount of research is currently investigating the effect of lifestyle on the risk of breast cancer, there is no clear evidence as yet that:

- Any lifestyle factor *causes* breast cancer
- Changing your lifestyle can *prevent* breast cancer
- Changing your lifestyle can *reduce* your risk of breast cancer

However, research has identified certain lifestyle choices that *may* influence breast cancer risk. This research has compared groups of women with and without a particular characteristic (such as women who consume a “low” compared to a “moderate/high” amount of alcohol) and has found differences between the two groups in the incidence of breast cancer (number of women who develop breast cancer).

So far, this type of research has *linked* a number of lifestyle factors with an increased incidence of breast cancer. These factors are high fat intake, moderate/high alcohol consumption, smoking, low levels of physical exercise and obesity (particularly in post-menopausal women).

These lifestyle factors may influence breast cancer risk as they affect hormone levels (for further information on the relationship between hormones and breast cancer see the section on Tamoxifen topic 4, page 14).

Further research is now needed to confirm if any of these lifestyle factors have a direct effect on breast cancer risk. In particular, there is currently little evidence that lifestyle affects the risk of breast cancer in women with a strong family history of the disease.

For further details of research investigating the effect of lifestyle on the risk of breast cancer see: (Although the following book was primarily written for American women, it does contain some useful information for British women)



Kelly, P T. 2000. *Assess Your True Risk of Breast Cancer*. New York: Henry Holt

If there is no clear evidence that lifestyle causes breast cancer, why should I maintain a healthy lifestyle?

There are a number of important reasons why you should try and maintain a healthy lifestyle:

- **To reduce your risk of developing other common cancers which are proven to be affected by lifestyle:**

For example

- Stopping smoking reduces your risk of developing lung cancer.
- A diet rich in fibre reduces your risk of bowel cancer.

- **To look after your General Physical Health:**

For example

- There is evidence that a healthy lifestyle reduces your risk of heart disease, lung disease and premature ageing of the skin.

- **To look after your General Psychological Health:**

For example

- There is evidence that exercise can help to relieve stress and depression.

By maintaining a healthy lifestyle, you can gain all those proven benefits for your overall health. As an added bonus, if future research shows that your lifestyle does affect your risk of breast cancer, you will have already been doing something positive to help reduce your risk of breast cancer.

How can I maintain a healthy lifestyle?

The following sections contain up-to-date guidelines on six aspects of maintaining a healthy lifestyle: diet, vitamin & mineral supplements, alcohol, smoking, sun and exercise. These guidelines are taken from the Health Education Board for Scotland leaflet "The Guide to Preventing Cancer", the Cancer Research Campaign leaflet "Reducing Risk" and from NHS Direct.

Diet

The sections below give advice on the types and proportions of the five food groups that are needed to form a healthy, well-balanced diet.



Fruit and Vegetables:

- Try to eat at least 5 portions of fruit and vegetables every day (this includes fresh, frozen, tinned and dried fruit and vegetables, and fruit juice).
- To increase your fruit and vegetable intake, substitute some of the meat in your main meal with kidney beans, replace some of the chips with salad or have fruit as a pudding.



Bread, Cereals and Potatoes:

- This food group includes bread, rice, pasta, breakfast cereals and potatoes- it should form the main part of each meal.
- To increase your intake of fibre, eat more wholemeal bread, wholemeal pasta, high fibre breakfast cereals and brown rice.



Meat, Fish and Alternatives:

- We only need to eat small portions of meat, fish, eggs, beans and lentils – they should fill about a quarter of your plate.
- Try to eat fish (fresh, frozen or tinned) 2-3 times per week, particularly oil-rich fish such as mackerel, sardines and salmon.



Milk and Dairy Products:

- We can eat these foods every day, but try to have low-fat varieties – about a half a pint of semi-skimmed milk or low-fat yoghurt per day is good for you.



Fatty and Sugary Foods:

- Try to avoid eating sweets, chocolate, biscuits, cakes, crisps and chips every day.
- When you do have them, only eat small amounts.

For further advice on healthy eating see:


  Health Education Board for Scotland “Eating for Health”, topic 10 page 42.


  Health Education Board for Scotland “Hassle Free Food”, topic 10 page 42.

Vitamin & Mineral Supplements

- For most people, the required types and amounts of vitamins and minerals are present in the foods they eat, therefore supplements are not normally necessary.
- For certain groups of people (e.g. pregnant women), specific types and amounts of supplements are recommended.
- If you are considering taking supplements, please seek medical advice from your GP first (too large a dose of supplements can be damaging to your health).

For further advice on taking vitamin and mineral supplements ask your GP or see:

 NHS Direct “Healthy Living: Eating for Health: Questions and Answers”, topic 10 page 43.

 NHS Direct on 0845 46 47.

Alcohol

- If you drink alcohol, do so in moderation – try to avoid drinking 3 or more units of alcohol per day on a regular basis.
- 1 unit of alcohol = ½ pint of ordinary strength lager, beer or cider.
= 1 small glass of wine or sherry.
= 1 single measure of spirits.



For further advice on reducing alcohol consumption:


 The Scottish Council on Alcohol on 0141 333 9677.

Smoking

- If you don't already smoke, don't start.
- If you smoke, try to stop – your risk of certain forms of cancer will immediately be reduced.

For further advice on stopping smoking see:

  Health Education Board for Scotland “Stopping smoking made easier”, topic 10 page 42.



 Smokeline on 0800 84 84 84.

Sun & Sunbeds

Take care to avoid getting sunburnt, whether you are on holiday or at home:

- Avoid being exposed to the sun between 11 a.m. and 3 p.m.
- Stay in the shade.
- Use a sunscreen with a sun protection factor (SPF) of at least 15.
- Wear a T-shirt and sun-hat.
- Avoid using sunbeds – the harmful effect of ultraviolet radiation on the skin from sunbeds is the same as from the sun.

For further advice on sun protection see:

  Health Education Board for Scotland “Take Care of Yourself in the Sun”, topic 10 page 42.



Exercise

- Regular exercise can help prevent you becoming overweight.
- Increasing physical activity can have both physical and mental benefits:

For Example

- Gives you more energy.
- Helps to strengthen your muscles, joints and bones.
- Improves your circulation.
- Gives you a sense of achievement.
- Helps you to sleep better.

For further advice on how to build more activity into your daily routine and improve your health see:

  Health Education Board for Scotland “Hassle Free Exercise”, topic 10 page 42.

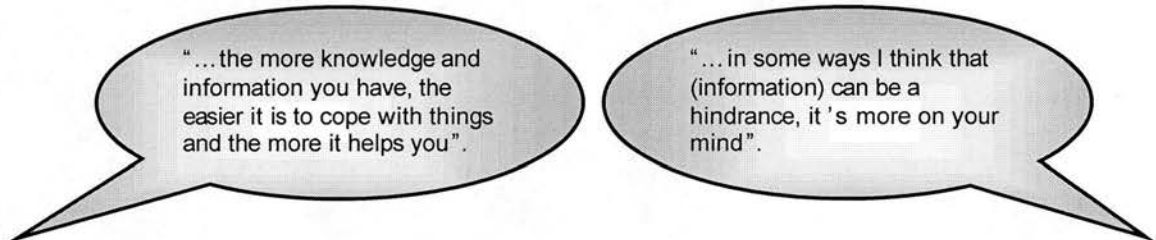
Topic 9: Worry about Breast Cancer

Introduction

This topic aims to help you recognise and cope with any worries you may have about breast cancer.

Although everyone worries at some time in their lives, people vary a lot in how much they worry and what they worry about. Some people describe themselves as “born worriers” whereas others don’t seem to worry about anything at all. However you would describe yourself, it is likely that learning about your increased risk of breast cancer has caused you some worry at some time.

Living with an uncertain situation such as an increased risk of breast cancer, can be particularly difficult to deal with and it may cause you to ask a number of questions about your situation. For some people, information that helps to answer these questions can reduce some of the uncertainty and perhaps help to relieve some of their worries. Other people may find that they cope better by trying to avoid thinking about their risk of breast cancer.



“... the more knowledge and information you have, the easier it is to cope with things and the more it helps you”.

“... in some ways I think that (information) can be a hindrance, it's more on your mind”.

We hope that by providing you with the up-to-date information we have included in the rest of this pack, we have given you the opportunity to have some of your questions answered.

However, you may have other questions that science is currently unable to answer. It is therefore a good idea to be aware of other ways to relieve the worry that these unanswered questions might cause. You may find that different ways may be more helpful at different times or for particular worries.

We have included a booklet produced by the charity “MIND” on “How to... stop worrying” for your information in the back of this pack. This booklet gives general advice on different ways to help reduce or control worrying.

In the following sections, we will talk about:

- Stress and the risk of breast cancer.
- Worries about breast cancer.
- Different ways to help relieve worrying.

Stress & the Risk of Breast Cancer: What does the research show?

Although there is a common belief that stress causes breast cancer, evidence of such a link from research is unclear.

However, recent research (Petticrew *et al.* 1999) has combined the results of all good quality studies conducted worldwide to investigate the relationship between stress and the risk of breast cancer. The combined results do not provide any evidence to suggest that experiencing a stressful life-event such as bereavement or divorce causes breast cancer.

In another recent study (Protheroe *et al.* 1999), 332 British women attending a breast clinic for a biopsy of a suspicious breast lump were asked about any stressful life events they had experienced in the last 5 years. The 106 women who were later diagnosed with breast cancer were no more likely to have experienced a very stressful event in the last 5 years than the 226 women who were found to have benign breast disease.

Although further research is needed to investigate the possible link between stress and breast cancer, the evidence so far suggests that stress does not cause breast cancer.

Worry about Breast Cancer

We recognise from our research that worry about breast cancer affects women in your situation to varying degrees and at different times. For example, some women describe their worries about breast cancer being triggered by things they experience in their everyday lives.

"I don't really think about it unless I'm confronted with it in somebody else or if it comes up on the television".

"I used to think I didn't worry about it but when the letter (for my appointment) comes in you do start".

We also recognise that women in your situation may have different sorts of worries about breast cancer and particular things may be more worrying for you at different times in your life.

"I do worry more from the children's point of view, you know if there's a genetic link then will they be affected?".

"... it is since I've had my daughter that it's started to prey on my mind (more) than it ever had before".

"... when I was approaching 40, it got a bit scary because that was the time when she (my mother) died (from breast cancer)".

(The quotes in speech bubbles were taken from one of our previous studies. For further details see topic 7, page 26).

As we said earlier, it is likely that learning about your increased risk of breast cancer has caused you some worry at some time. A certain amount of worry about breast cancer only seems natural for women in your situation. But how do you recognise if worrying about breast cancer begins to get out of control? It may be helpful to ask yourself the following questions:

- How much time am I spending worrying about breast cancer?
- To what extent is worrying about breast cancer interfering with my daily life (e.g. how bad are the physical or psychological effects of worrying that I'm experiencing?) (for more information on the physical and psychological effects of worrying, see the MIND booklet "How to... stop worrying" at the back of this pack).

If you can recognise when worrying about breast cancer is getting out of control, you can then take steps to help reduce the worry and prevent it reaching those levels again.

Common Worries about Breast Cancer: What can I do?

Although there are many different sorts of worries about breast cancer, we have identified some of the common worries you might have and have provided practical ways that might help to relieve those worries.

Worry about symptoms



If you are worried about a change in your breasts, please make an appointment in the first instance to see your GP and if it is appropriate they will then refer you to the Ardmillan Clinic. Do remember that most changes in the breasts will turn out to be benign and therefore harmless.

Worry about a change in your family history



If you are worried about a change in your family history of breast cancer and the implications this could have for your own risk or the risk of other family members, you can telephone one of the nurses from the Ardmillan Clinic on 0131 651 1805.

Worry about what you have read in the newspapers or seen on the television



The media frequently report on research about breast cancer, particularly about the causes of breast cancer. You may find that hearing these reports sometimes causes you concern. Here are a few suggestions of things to think about when you see or hear reports of this kind, to try to minimise the worry it may cause you:

- **Remember that headlines are often used to grab our attention** to boost newspaper sales or television ratings. Headlines don't always give an accurate summary of the information, particularly if it is a scientific or medical story.
- **What exactly do the results show?** It is important to consider the information you are given carefully. Look at what the report does *not* say as well as what it does say. For example, if research shows that eating 10 chocolate bars a day is *associated* (or *linked*) with breast cancer, it only means that these two things have been seen together. It does not mean that one has been shown to cause the other. (For further information on lifestyle and diet, see topic 8, page 27).

- **How many people took part in the study?** Studies where only small numbers of people participated may need to be tested with more people before we can have confidence in the results. When a new scientific discovery is made, there is always a period of time when other scientists need to check if they can get the same results by following the same procedures. Although these subsequent studies are also important, they don't often attract media attention. When a new medical treatment is announced, there is usually a long process of testing the new treatment on large numbers of people before the treatment can become available. These checks are extremely important to ensure the safety of a new treatment.
- **Who were the people who took part in the study?** Do these people differ from you in terms of their age, nationality etc.? This is relevant to how confident you can be that the results might apply to you. For example, although there is good evidence that breast screening is useful for women over 50 years, further research is still needed to find out if it is useful in younger women (for further information on breast screening, see topic 4, page 12).
- **Where was the study published?** Check to see if the results of the study have been published (if they have the reporter should mention where they were published). Respected scientific journals like "Nature" or medical journals like the "Lancet" or "British Medical Journal" will have sent the study to other leading researchers for their opinion before agreeing to publish it.
- **Who funded the study?** This could bias the results if the organisation has a vested interest in the outcome of the study. For example, suppose a dairy company funds a study whose results show that the calcium which is contained in dairy products prevents breast cancer. As the dairy company stands to benefit from these results, it raises the question of whether the study might have been biased in some way to obtain these results.
- **Statistics can be misleading.** Many different forms of statistics may be given in a report. Sometimes one statistic may be given without anything to compare it with. For example, a report could read "*New Treatment for Breast Cancer Cures 1,000 Women*". Your reaction to this piece of information may be different if you knew that the treatment had not cured 9,000 other women, or if existing treatments that are already available are just as effective as the new treatment. If you really want to understand statistics you need to be sure you know how the figures were collected, when and by whom so that you can place them into some sort of context.

For further information on understanding statistics see:



Cancer Research Campaign: Cancer Help UK "About Cancer: cancer statistics", topic 10 page 41.

What other things can I do to help relieve worry?

The following sections suggest a number of different ways that can help reduce worry. These include ways to help yourself and ways of getting help from others. Many of these different ways are described in more detail in the MIND booklet “How to... stop worrying” which we have included in the back of this pack.

Helping Yourself

- **Taking action:** For some worries there maybe something that you can practically do to help relieve the worry such as make an appointment with your GP.
- **Confronting worry:** If you can confront a worry, you can look at how you could cope, what you could do and who could support you if the worst happened.
- **Listing worries:** It may be helpful to write your worries down with reasons why the things you are worried about may never happen.
- **Remember positive information:** It may be helpful to remind yourself of current scientific knowledge about breast cancer. Focus on positive points which are relevant to you. You may find it helpful to write these on a list so that you can read them when you feel yourself becoming worried.
- **Controlling worry:** Try limiting your worries to certain times of the day or to a specific place.
- **Talking about your worries:** You might find it helpful to talk to someone about your worries. This could be a member of your family, a close friend or a counsellor (see the following section on psychological therapies page 40).
- **Healthy Lifestyle:** Physical exercise and cutting down on caffeine-based drinks can help relieve worry. When you are worried, it is easy to forget about what and when you eat. It is particularly important to eat healthily and not miss out meals (for more information see topic 8, page 29).

For further information on how diet can affect your psychological well-being see:



MIND “The MIND guide to food and mood”, topic 10 page 43.

- **Make time for yourself:** Making time for leisure activities that you enjoy, such as soaking in a hot bath or listening to music, can distract you from your worries and also help to relieve the physical symptoms of worry.

- **Relaxation:** Relaxation can help control the level of worry you experience and can be a useful way of relieving the physical symptoms of worry. The following simple relaxation exercise is from the “The Mind guide to...managing stress” and should take about 5 to 10 minutes.

Simple relaxation (with deep breathing):

- Have a stretch. Then let your shoulders and arms relax into a comfortable position. Shrugging, wriggling and shaking all help your muscles to stop tensing and to relax.
- Ease off the tension in your feet, ankles, calves, knees, thighs, chest, arms and neck.
- If you are sitting in a chair, or lying on the floor, allow yourself to feel as if the chair or the floor is supporting your whole weight; feel yourself letting go.
- Try to be peaceful, loosen your jaw and face. A bland expression will help your face muscles to relax.
- Become aware of your breathing, its rhythm, depth or shallowness and its speed.
- Put one hand on your upper chest, and one just below your ribs on your abdomen.
- Slowly let out your breath.
- Gently breathe in, so that you feel your abdomen rise slowly under your hand (if you find that only the hand on your abdomen moves, then you are breathing correctly; the abdomen is moving as your diaphragm rises and falls rhythmically. You should find little or no movement in your upper chest; your hand should stay still).
- Breathe out again, feeling your abdomen fall, and make sure you exhale a little longer than you inhaled.
- Pause for a few moments and then repeat the breathing exercise again.
- Close your eyes and imagine a peaceful scene – an exotic, desert island, the shady depths of a forest or sunlight glistening on a lake.
- Choose your own special place, whatever seems most restful to you. Then for a few moments, imagine that you are really there.

- **Complementary and alternative therapies:** These can help you to relax and relieve the physical symptoms of worry such as sleeping problems. They include herbal remedies and physical therapies such as aromatherapy. They can be used as an alternative or alongside conventional medical treatment. It is a good idea to get advice from your GP before starting any therapy.

For further information on complementary and alternative therapies please ask your GP or see:



MIND “A-Z of Complementary and Alternative Therapies”, topic 10 page 43.

Getting Help From Others

Some people may find that they need additional help as the things they can do to help themselves are not enough. It may then be a good idea to seek some advice from your GP. They may either help you themselves or refer you to a counsellor, psychologist or other specialist for help.

- **Psychological therapies:** These are often called “counselling” or “talking therapies” as they give you the chance to talk about your worries. They can also help to teach you how to control worrying.

For further information on psychological therapies see:



MIND “Understanding Talking Treatments”, topic 10 page 43.

- **Medical treatment:** Medication can often help to relieve periods of extreme worrying. However, it does not help in identifying the cause of the worry, can have undesirable side-effects and can be addictive.

For further information on stress, anxiety, depression and bereavement see:



MIND “How to...look after yourself”, topic 10 page 43.


“The Mind guide to...managing stress”.

“Understanding anxiety”.

“Understanding depression”.

“Understanding bereavement”.



 Health Education Board for Scotland “Talking about stress”, topic 10 page 42.

“Talking about anxiety”.

“Talking about depression”.

“Talking about bereavement”.


Topic 10: Sources of Information

Organisations:


The following section lists organisations in alphabetical order where you can obtain the suggested further reading and organisations where you can obtain additional relevant information.

Although there are a large number of organisations and websites providing information about breast cancer, we have just listed a small number here, those we feel may be most useful.

Most of the organisations we have listed are British but a few are American (although not all of the information given by the American organisations will be applicable for British women, we still felt that their websites provide useful information).


-  If you haven't got access to the Internet at home, many local libraries are now providing Internet access and training.


American Cancer Society


 Website: <http://www.cancer.org/>


Includes an online cancer resource centre full of information about cancer.

Breast Cancer Care (Scottish Office)


 46 Gordon Street
Glasgow G1 3PU

 Tel: 0141 221 2233

 Helpline: 0808 800 6000


 Fax: 0141 221 9499

 E-mail: breastcancercareScotland@BTInternet.com

 Website: <http://www.breastcancercare.org.uk>



Offers information and support to those affected by breast cancer or other breast health concerns.

The Breast Cancer Fund (U.S.A)

 Website: <http://www.breastcancerfund.org/>


An American charity that provides information about breast cancer.

CancerBACUP (Scottish local centre)

 2nd Floor
30 Bell Street
Glasgow G1 1LG
 Tel: 0141 553 1553
 Fax: 0141 553 2686
 E-mail: jennyw@cancerbacup.org
 Website: <http://www.cancerbacup.org.uk>






Offers information and support to people with cancer, their families and friends.

CancerNet – National Cancer Institute (U.S.A)

 Website: <http://www.cancernet.nci.nih.gov/>


An online information service provided by the American National Cancer Institute containing comprehensive information about cancer and genetics.

The Cancer Research Campaign

 10 Cambridge Terrace
London NW1 4JL
 Tel: 020 7224 1333
 E-mail (for information leaflets): publications@crc.org.uk.
 General Website: <http://www.crc.org.uk>
 Specific Website for information about cancer: <http://www.cancerhelp.org.uk>

The Cancer Research Campaign provides an Internet information service about cancer and cancer care for the general public called "Cancer Help UK".

Genetic Information Systems (genISYS) (U.K)

 Website: <http://www.cee.hw.ac.uk/genisys>

This website provides information and Internet resources about cancer genetics screening from the South East Scotland Clinical Genetic Service. The site is for Patients, General Practitioners, Geneticists and other Healthcare Workers. The areas of interest to non-medical users should be easy to use and follow, but the language in some areas, aimed primarily at medical users, may tend to be technical.

The Genetic Interest Group (U.K.)Website: <http://www.gig.org.uk>

The website of a British alliance of over 120 charities which support children, families and individuals affected by genetic disorders. Provides information on genetics and links to other genetics websites.

The Health Education Board for Scotland

(information leaflets are available in GP surgeries, hospital information centres or from:)



Health Promotion Library Scotland
Health Information Division
Health Education Board for Scotland
The Priory
Canaan Lane
Edinburgh EH10 4SG



Tel: 0845 912 5442

E-mail: library.enquiries@hebs.scot.nhs.ukWebsite: <http://www.hebs.scot.nhs.uk>

Provides health information for the general public.

Hereditary Breast Cancer Helpline (U.K.)

Tel: 01629 813000 (answer phone available outside office hours)

Provides information and support to anyone concerned about hereditary breast cancer.

Imperial Cancer Research Fund - Cancer Information Service

P.O. Box 123
Lincoln's Inn Fields
London WC2A 3PX

Email: cancer.info@icrf.icnet.ukWebsite: <http://www.imperialcancer.co.uk>

Provides a wide variety of information on cancer for the general public.

InTouchLive (U.S.A)Website: <http://www.intouchlive.com>

An online American magazine dedicated to information about cancer and written by cancer experts. Includes a useful section on "Myths & Facts about Breast Cancer".

Maggie's Cancer Caring Centre

 The Stables
Western General Hospital
Crewe Road
Edinburgh EH4 2XU
 Tel: 0131 537 3131
 Fax: 0131 537 3130
 E-mail: maggies.centre@ed.ac.uk
 Website: <http://www.maggies.ed.ac.uk>



Offers information and support to cancer patients and their families.

MIND (National Association for Mental Health)

 15-19 Broadway
London E15 4BQ
 Tel: 020 8519 2122
 MindinfoLine: 0845 766 0163
 Website: <http://www.mind.org.uk>


Provides information on various aspects of mental distress.

NHS Direct (U.K.)

 Helpline (24-hour): 0845 46 47
 Website: <http://www.nhsdirect.nhs.uk>


Provides healthcare advice and information on a range of health concerns.

Patient UK

 Website: <http://www.patient.co.uk>

A directory of UK websites that provide information on health, disease and illness.

The Royal Marsden Hospital (U.K.)

 Website: <http://www.royalmarsden.org.uk>

Patient information service from the U.K's leading comprehensive cancer centre.

The Scottish Association for Mental Health - Information Service



Information centre

Cumbræ House

15 Carlton Court

Glasgow G5 9JP



Tel: 0141 568 7000 (2 - 4.30 p.m., Monday to Friday only)



Fax: 0141 568 7001



E-mail: info@samh.org.uk



Web site: <http://www.samh.org.uk>

Provides information on mental health and relevant services in Scotland.

UK Breast Cancer Awareness Website



Website: <http://hosted.aware.easynet.co.uk/>

Patient information website which includes a list of all U.K breast cancer organisations and book reviews.

Additional References: (additional scientific and medical journal articles and books we have used to write this information pack)



To obtain scientific and medical journal articles, please ask at your local public or university library. Some journals such as the "British Medical Journal" are also available online (<http://www.bmj.com>).



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3 published leaflets to accompany the information pack (Appendix III):

- "Cancer genetics" (South East of Scotland Clinical Genetics Service, 2001)
- "Breast awareness" (Breast Cancer Care, 2000)
- "How to... stop worrying" (MIND, 1998)

GENETIC TESTING

Should I be tested for a faulty gene:

If you have a strong family history of breast cancer, ovarian cancer, or bowel cancer, it may be possible to offer you a genetic test. It is important to remember that there is no pressure on you to have this test. If you are interested in it, all the important implications will be discussed beforehand. If you decide not to have the test but are at a greater risk of an inherited form of cancer than the general population, you may still be eligible for extra screening.

What happens if I have the test and discover I have the faulty gene:

Your risk of developing an inherited form of cancer is high. So you may wish to take up the option of extra screening because early detection and treatment of cancer usually improves your outcome. In some cases you may be able to join research studies aimed at preventing the development of the disease. You may also consider surgery to reduce the risk.

What happens if I have the test and do not have the faulty gene:

Your risk of developing cancer is the same as anyone else of your age. You are encouraged to join the standard population screening programmes, where appropriate.

For instance there is a National Breast Screening Programme for women over the age of 50.

Where do I get further information:

If you think you fit into one of the groups for the screening programmes listed, or if you have a strong family history of breast, ovarian or bowel cancer you may ask your GP to refer you to your local NHS clinical genetics service for risk assessment.

If you would like further information contact:-

**South East of Scotland
Clinical Genetic Service
Western General Hospital
Crewe Road
Edinburgh
EH4 2XU**

Tel 0131 651 1012

Fax 0131 651 1013

CANCER GENETICS

Genes are the blueprints of life which are passed down from generation to generation. They determine characteristics such as whether you are tall or short, dark or fair-haired.

A very small number of cancers (5 to 10 percent) may be caused by faulty genes which are inherited at birth. But, even if one is in your family, it does not mean you will automatically have it.

This leaflet gives pointers on whether a cancer is likely to be caused by an inherited faulty gene. It outlines screening programmes for those at increased risk of this developing and tells you about genetic testing for faulty cancer genes.



WESTERN
GENERAL
HOSPITALS
NHS TRUST
EDINBURGH

A WAY OF DIAGNOSING SOME CANCERS EARLY AND TRYING TO PREVENT THEM

Is a family history of cancer important:

Where several cases of cancer occur in the same family it is natural to wonder whether there is an inherited factor. The pointers to a cancer which may be running in a family are:

- The number of people in the family who have developed breast, ovarian and bowel cancers.

The more people in the family who have developed one of these cancers, the more likely it is to be due to the inheritance of a faulty gene.

- The age at which the cancer developed.

The younger the person when diagnosed, the more likely it is to be due to hereditary factors.

- The pattern of different types of cancer seen in the family.

We sometimes see breast and ovarian cancer running together in the same family, or ovarian and bowel cancer.

Adding these pointers together we can work out if you are likely to have an increased risk of developing cancer from an inherited faulty gene.

Your first degree relatives are your mother, father, sister, brother, daughter and son.

Your second degree relatives are your grandmother, grandfather, grandchild, aunt, uncle, niece and nephew.

Bowel Cancer

Your risk of developing cancer of the bowel is moderately increased if you have one of the following:

- A first degree relative with bowel cancer diagnosed under 45.
- Two first or second degree relatives on the same side of the family with bowel cancer, one diagnosed under 55.
- 3 or more affected first or second degree relatives

If you fit one of these groups you may be able to enter a screening programme. This will involve regular examination of the bowel using a flexible telescope (called a colonoscope) to try and detect early cancer.

Breast Cancer

Your risk of developing breast cancer is moderately increased if you have one of the following:

- A first degree relative with breast cancer diagnosed under 40.
- Two first or one first and one second degree relative on the same side of the family with breast cancer diagnosed under 60 or with ovarian cancer.
- Three first or one first and two second degree relatives on the same side of the family with breast or ovarian cancer.

- A first degree relative with breast cancer in both breasts or breast and ovarian cancer.
- A first degree **male** relative with breast cancer.

If you fit one of these groups you may be able to enter a screening programme. This will involve regular mammograms, which are X-rays of the breast, to try and detect early cancer.

Ovarian Cancer

Your risk of developing ovarian cancer may be increased if you have one of the following -

- Two first degree relatives or one first and one second degree relative on the same side of the family with ovarian cancer
- A first degree relative with breast and ovarian cancer.
- One first degree relative with ovarian cancer and one first or second degree relative with breast cancer on the same side of the family diagnosed under 50.
- One first degree relative with ovarian cancer and two first or second degree relatives with breast cancer on the same side of the family diagnosed under 60.

If you fit one of these groups you may be able to enter a screening programme. This will involve regular screening with an annual ultrasound and a blood test to try and detect early cancer.

Breast Cancer Care is the national organisation offering information and support to those affected by breast cancer or other breast health concerns. Our services are free, confidential and accessible.

For more information about our services, or to talk in complete confidence, telephone the Breast Cancer Care helpline on 0808 800 6000.



Breast Cancer Care
— Helpline —
0808 800 6000
Information • Support



Breast Cancer Care

Breast awareness

Information • Support
—
when you need it

Breast Cancer Care is a national organisation offering information and support to those affected by breast cancer. Its services are free, confidential and accessible, and include:

- a national helpline - run by specially trained nurses and volunteers
- information - booklets, factsheets and a website
- volunteer services - providing one-to-one emotional support for women and men with breast cancer and their partners, and volunteer support and outreach networks for women from minority ethnic communities, lesbian and bisexual women, women from socially deprived communities and younger women
- aftercare services - including prosthesis fitting, telephone support groups for younger women and women with secondary breast cancer, and support services for those living with breast cancer
- regional services - providing local information, aftercare services and local volunteers in Scotland and the north of England.

Breast Cancer Care
— Helpline —
0808 800 6000
Information • Support

Central Office

Breast Cancer Care

Kiln House 210 New Kings Road

London SW6 4NZ

Telephone 020 7384 2984 (administration)

Fax 020 7384 3387

E-mail bcc@breastcancercare.org.uk

Website www.breastcancercare.org.uk

Scotland Office

Breast Cancer Care

46 Gordon Street Glasgow G1 3PU

Scottish services 0141 221 2233

Fax 0141 221 9499

E-mail breastcancercareScotland@BTInternet.com

Breast Cancer Care helpline

0808 800 6000

Breast Cancer Care is committed to equal opportunities and access for all.

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Know what is normal for you

Your breasts will go through many perfectly normal changes throughout your lifetime. They are affected by hormonal changes during your menstrual cycle, pregnancy, breast-feeding, the menopause (change of life) and weight loss or weight gain.

The menstrual cycle

Each month, during your child-bearing years, your breasts prepare for pregnancy and breast-feeding. Breasts often become enlarged, tender and lumpy shortly before a period starts but return to normal once the

period is over (although some women may have tender, lumpy breasts throughout their cycle).

The menopause

Breast tissue changes after the menopause; it is often less dense and firm, and becomes more fatty, making your breasts feel softer. As you grow older your breasts may get smaller. If you take HRT (hormone replacement therapy) your breasts may feel firmer and sometimes quite tender.

The breast awareness 5-point code

1. Know what is normal for you
2. Know what changes to look and feel for
3. Look and feel
4. Report any changes to your GP without delay
5. Attend for routine breast screening if you are 50 or over



What changes should I be aware of?

These are the changes that you should be aware of when you look at and feel your breasts:

- a change in size - it may be that one breast has become noticeably larger or noticeably lower
- a nipple has become inverted (pulled in) or changed its position or shape
- a rash around the nipple
- discharge from one or both nipples
- puckering or dimpling of the skin
- a swelling under your armpit or around your collarbone (where the lymph nodes or glands are)
- a lump or thickening in your breast that feels different from the rest of the breast tissue
- constant pain in one part of your breast or in your armpit.

What shall I do if I find a change?

You will know better than anyone how your breasts feel and look normally, so if you do notice a change, see your GP as soon as possible.

Don't worry that you may be making an unnecessary fuss, and remember that most breast changes will be benign (non-cancerous) and harmless.

When your GP examines your breasts s/he may be able to reassure you that there is nothing to worry about. (If s/he thinks the change may be connected with your hormones, your GP may ask you to come back at a different time in your menstrual cycle.)

Alternatively, s/he may decide to send you to a breast clinic for a more detailed examination.

For more information about benign breast problems, what happens at a breast clinic and the tests used to make a diagnosis, see Breast Cancer Care's booklet *Making a diagnosis: breast problems and breast cancer*.

If you want more information or practical advice about being breast aware, contact your practice nurse at your GP surgery.

Screening for breast cancer

If you are between 50 and 64 you are entitled to be screened every three years as part of the National Breast Screening Programme.

Your name will be taken from your GP's list and you will be sent an invitation to come for a mammogram (breast x-ray). This may not happen the year you turn 50 but it will within three years of you turning 50.

At present younger women are not invited for screening as part of the NHS programme. A clinical trial is underway to look at whether the NHS breast-screening programme should be extended to include younger women.

However, breast screening is available for women over 40 from private health-screening centres.

If you are 65 or over you will not be invited for screening. However, you are still at risk of breast cancer and entitled to free breast screening every three years on request. All you need to do is ask your GP or practice nurse to arrange an appointment for you, or you can contact the breast-screening unit yourself.

You can find out where your local breast-screening unit is by calling the free Health Information Service on 0800 665544 (or the NHS Health Helpline on 0800 224488 in Scotland), or by contacting your GP practice.

Being breast aware

Every woman should be breast aware throughout her adult life. It is an important part of caring for your body.

Being breast aware means knowing how your breasts look and feel normally so that you notice any change that might be unusual for you. Detecting a change early means that if cancer is diagnosed any treatment may well have a better outcome. Most breast changes will prove to be benign (non-cancerous) but you should always report any concern to your GP.

Men too need to be aware of any changes in their breast tissue, as approximately 200 men in the UK get breast cancer each year.

Becoming breast aware

Breast awareness is about becoming familiar with your normal breast tissue and how it changes, for example at different times of the month.

Get into the habit of looking at and feeling your breasts from time



to time. One way of looking is by using a mirror so that you can see your breasts from different angles. You may find feeling your breasts is easier to do with a soapy hand in the bath or shower, or you may prefer to do it lying down. You can decide when is convenient for you and what you are comfortable with.

How to... find out more

Mind is the leading mental health charity in England and Wales. It works for a better life for people diagnosed, labelled or treated as mentally ill.

It does this through campaigning, community development, training, publishing, and a comprehensive information service.

Throughout its work Mind draws on the expertise of people with direct experience as providers and users of mental health services.

For details of your nearest Local Mind association contact the regional office in your area.

North West Mind: 21 Ribblesdale Place, Preston PR1 3NA
Northern Mind: 58 Durham Road, Gateshead, Tyne & Wear NE8 4EL
South East Mind: Kemp House, 1st Floor, 152-160 City Road, London EC1V 2N
South West Mind: 9th Floor, Tower House, Fairfax Street, Bristol BS1 3BN
Trent & Yorkshire Mind: 44 Howard Street, Sheffield S1 2LX
Mind Cymru: 23 St Mary Street, Cardiff CF1 2AA
West Midlands Mind: 20/21 Cleveland Street, Wolverhampton WV1 3HT
Northern Ireland Association for Mental Health, Central Office, Beacon House, 80 University Street, Belfast BT1 1HE (01232 23/93/ helpline)
Scottish Association for Mental Health, Cumbræ House, 15 Carlton Court, Glasgow G5 9JP (0141 568 7000)

Mind (National Association for Mental Health)
15-19 Broadway, London E15 4BQ, Tel. 0181 519 2122, Fax. 0181 522 1725,
MindinfoLine 0181 522 1728 London, 0345 660 163 outside London

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Publications

This booklet was written by Louise Flory

HOW TO...

stop worrying



Mental Health
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How to... *stop worrying*

“ I think of myself as a born worrier. I've always worried ever since I was little. I'd worry about what people at school thought about me and about homework and all sorts of things. **”**

“ I worry so much that for my last birthday a friend bought me a plaque with the slogan 'Worrying is like riding a rocking horse – it doesn't get you anywhere'. **”**

“ As a child every night when I went to bed I would worry about members of my family dying. I am not religious but I ended up saying a prayer each night which was basically a list of my worries which I asked God to take care of. This helped me to go to sleep. As I grew up the list of worries became so long that I used to worry about going to bed. The 'prayer' took so long and there was so much to remember. In the end it was a worry off my mind when I stopped saying the prayer. **”**



Worrying means spending a lot of time thinking about bad things – being preoccupied with negative possibilities. The more you worry the larger your worries become. You may even find yourself worrying about all the time you have spent worrying. There are many different types of worries; they include worries about things that might happen in the future, worrying about things that are actually taking place, and retrospective worry about events that have already passed.

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Useful organisations

British Association for Counselling 1 Regent Place, Rugby, Warwickshire CV21 2PJ, tel. 01788 578328. *Will send a list of trained counsellors in your area if you write enclosing an A5 sae.*

British Association for Behavioural and Cognitive Therapy PO Box 9, Accrington, Lancashire BB5 2GD. *Can provide information on CBT and how to find practitioners.*

Institute for Complementary Medicine PO Box 194, London, SE16 1QZ, tel. 0171 237 5165. *Provides information and can send out a list of practitioners if you enclose a sae.*

NO PANIC 93 Brands Farm Way, Randlay, Telford, Shrops TF3 2JQ, Helpline 01952 590545 10a.m.-10p.m. *Help with panic attacks.*

Stress Management Training Institute Tel. 01983 868166 for information on relaxation classes. *Produces leaflets and cassette tapes to help you relax.*

Further reading and order form

Qty

- ☐ **Manage Your Mind: The Mental Fitness Guide** G. Butler & A. Hope (Oxford University Press 1995) £7.99
- ☐ **Overcoming Anxiety: A Self-help Guide Using Cognitive Behavioural Techniques** Helen Kennerley (Robinson 1997) £6.99
- ☐ **Managing Stress** Ursula Markham (Element 1996) £6.99
- ☐ **Overcoming Panic** D. Silove & V. Manicavasagar (Robinson 1997) £6.99
- ☐ **Anxiety, Phobias & Panic Attacks** E. Sheehan (Element 1996) £4.99
- ☐ **Stress Management – A Comprehensive Guide to Wellness** E. Charlesworth & R. Nathan (Souvenir 1997) £10.99
- ☐ **Panic Disorder – The Facts** S. Rachman & P. de Silva (Oxford University Press 1996) £7.99
- ☐ **Secrets of Self-Esteem** P. Cleghorn (Element 1996) £6.99
- ☐ **How to Assert Yourself** (Mind 1996) £1
- ☐ **How to Cope with Panic Attacks** (Mind 1997) £1
- ☐ **How to Cope with Sleep Problems** (Mind 1998) £1
- ☐ **How to Look After Yourself** (Mind 1996) £1
- ☐ **Understanding Anxiety** (Mind 1998) £1
- ☐ **Understanding Phobias and Obsessions** (Mind 1998) £1
- ☐ **A-Z Complementary & Alternative Therapies** (Mind 1995) £2.50
- ☐ **The Mind Guide to Managing Stress** (Mind 1998) £1

Worries about what might happen

These worries include concerns about things that could possibly happen, and things that very probably won't happen. For example, despite the fact that it is statistically unlikely, you may worry about whether you will have a car accident, or catch a fatal disease. Worries about what might happen in situations over which you have some control can also be very troubling. You might be very worried that you're going to fail an exam or not meet a deadline because of not putting in enough work. If you were able to stop worrying and do some work the likelihood of a bad outcome could decrease.

Worries about things that are happening

Again, these can include feelings of anxiety both about situations that you can change, and those you are powerless to change. Example of the latter would be worrying about the fact that you are caught in traffic, or that your train has been delayed. An example of the former would be worrying about a persistent cough; if you go to the doctor your mind could be put at rest, or you could be given the relevant treatment, both of which are better than worrying.

Worries about things that have happened

There is often nothing that can be done about these worries. An example of this would be worrying about whether you have failed an exam, or made a mistake at work.



Almost everyone worries. A certain amount of worrying is a healthy response to life; it can prevent us being reckless, or stimulate us to do our best or to take control of a situation. However, some people worry a lot more than others, and sometimes to the point that it has a negative effect on their lives.

How to... *stop worrying*

*Why do
we worry*

'I think my worrying has a lot to do with my lack of self-confidence. Although it's hard to admit, it's often easier for me to worry about something than to do something about it. Over the years I've learnt that the less time I give myself to worry and the quicker I act the better. I may feel ill before I make that phone call and shake a bit afterwards but when it's over I feel so much better, having blasted a worry – however small – into oblivion.'

Worries are basically fears. Everyone gets scared, but we all handle fear in different ways. Sometimes it is easier to dwell on a fear than to do something about it, or to accept that there is nothing to be done. This may be because of a lack of confidence – we may not believe we are capable of taking action or handling a bad situation. (If this seems to be the case for you, you might find Mind's booklet *How to Assert Yourself* useful; see Further reading p. 10.)

*What effects
can worry
have*

Physical effects

Our bodies react chemically to the fear which worrying entails. When we are scared our bodies release adrenalin in what is called a 'fight or flight' response which nature evolved to enable us to counter or to escape threats. This adrenalin affects the digestive system, and can make you feel ill. The more you worry the worse it gets, and a real 'rush' of adrenalin can lead to you having 'butterflies in the stomach', a headache, or feeling very sick and being unable to eat.

Worrying can make it very difficult to go to sleep, as worries often come on at their strongest at night. When you're trying to go to sleep there's nothing to distract you from the worries that may have been lurking in the background. It is then very easy to start feeling anxious about the sleep you are missing through having these thoughts. In addition, at night, especially if alone, it is easier for concerns to get out of perspective, and of course harder to do something about them. We also worry more when we are tired. (If worrying affects your sleep, you may find Mind's booklet *How to Cope with Sleep Problems* helpful; see Further reading p. 10.)

Distraction

When you are about to go into a situation which worries you, such as a doctor's appointment or a job interview, it can be useful to focus on something other than the problem in hand. This could be as simple as picking up a good book or a listening to a personal stereo. If you feel a worry taking hold you could push it out of your mind by looking at other people and imagining their lives, or by really examining your surroundings in a very detailed way.

Physical exercise

Worrying means we are overly concerned with what's going on in our heads, and exercising can help to focus us on our physical sides instead. It can also help to relieve the tension associated with worrying by using up the adrenalin produced. You don't have to go for a long run or to the gym; a good steady walk can be just as effective, and it's good for your heart as well as your head. Worry beads and stress toys can be useful as a kind of 'portable exercise'. They can be used both as a distraction and to relieve tension.

Dietary changes

It helps to cut down on tea, coffee and other caffeine-based drinks such as colas and canned drinks. These are stimulants, and can heighten the physical effects of worry, such as headaches and stomachaches.

Medication

Sometimes antidepressants or minor tranquillisers are prescribed for people where extreme worrying has manifested itself as anxiety. Both forms of medication have side-effects and minor tranquillisers especially can be addictive. Medication can be effective in easing the burden in times of extreme anxiety, but do not help to get at the 'root' of continuous and perpetual worrying.

Complementary therapies

A growing number of people use herbal remedies such as the Bach Flower Remedies, or homoeopathic preparations (now available in many high street chemists). There are also physical therapies such as acupuncture, reflexology and aromatherapy which some people find useful. Yoga or meditation classes can be effective; they can teach you to relax your muscles and breathe more deeply in order to control the shallow breathing and rapid heartbeat often associated with worrying.

Prioritising and taking action

There is often something we can do about a situation we feel anxious about. Consider each preoccupying thought one by one, and then consider whether there is something that could be done about it. Make a list of these possible actions, with the actions for the most concerning worries at the top. It can then be possible to work slowly through the list, concentrating on one thing at a time. Cross out the action once it has been completed, to reflect the fact that you have acted positively and dealt with a worry.

If you're not sure what would be the best action to take you could try making a list of possible actions along with their advantages and disadvantages. As well as helping you make a decision, this could help you feel more confident about what you decide to do.

Self-assertiveness

You may feel that there is something that you could do about a particular worry but that you are not confident enough to do it. In this instance self-assertiveness classes may help.

Controlling worries

You could try allocating certain times and places to your worries. For this to work it is important to be strict, and not let worries intrude on your thoughts at other times. It might be helpful to try to visualise a box to put your worries in that you can open at a later date or time. Some people set aside say thirty minutes a day for worrying, taking quite literally the phrase 'I'll worry about that later'. It is helpful if you set this period at the same time of the day/week, and have it in the same place.

Relaxation

Relaxation exercises are useful in dealing with anxious feelings, often involving trying to replace negative worrying thoughts with positive ones. This can include imagining somewhere where you would like to be – an ideal beach, garden or home. You could also try seeing your worries as actual objects that you can discard – for example, stones that you can throw into the water. Unfortunately sometimes trying to do a relaxation exercise itself can be worrying. You might feel that it's not working or that you're doing it wrong. It's best to take the attitude that you're just 'giving it a go' and that these negative thoughts are normal. It may sound surprising, but relaxation can take a lot of practice to get right.

Psychological effects

Worries can make you feel very helpless; the more worries you have the less able you feel to cope with them. This reduces confidence and makes us more vulnerable to feelings of anxiety. A lack of self-confidence can affect how people relate to you, and how you feel in response. In this way a kind of negative spiral sets in, and some people experience panic attacks as a result of the build-up of these kind of feelings. (See Useful organisations p.10 and Further reading p.10 for help with panic attacks.)

Worries also make it very difficult to concentrate and carry on with everyday life, so that problems build up. It can be very emotionally draining to feel constantly anxious. Sometimes it can feel as though worries have taken over your life. In order to assert some sort of control some people may develop behaviour that could be described as obsessional. An example of this would be checking that a door was locked many times before being able to leave the house. Some people may also develop eating disorders as a way to control their anxiety.



'Many people think that worrying is a complete waste of time. Personally I don't think that's true. It seems to me that if I worry and think about the worst that could possibly happen the outcome is rarely as bad as I've imagined.'

If something is 'niggling' at you and you try to disregard it but it keeps bringing itself to your attention, this can be a helpful push to do something about it. For example, you might have a mole on your skin that you are worried about; you try to ignore it but can't, and this forces you to visit the doctor. Sometimes worry makes us act and this can be positive. Also, worrying about the worst that could happen can help us to deal with and prepare for what does take place.

The adrenalin that is sometimes released through worrying can be helpful. For example, if someone is worried about a race they are about to take part in the adrenalin might give them the extra push they need to succeed. However, if they get *too* worried it could mean that they feel ill and unable to perform.

Having the occasional worry for a short period of time is very different to worrying about several things every day or having a worry that seems to dominate everything. These worries can make us too anxious to be able to think and act in a useful way – and this is when the worries themselves become the problem.

Confronting the worst that could happen

It can be useful to visualise the worst thing that could happen in any worrying situation. Often a worry is a fear of the unknown, and trying to *define* that fear can help overcome it. Having confronted the worry or fear for what it is, it is sometimes easier to know what to do about a situation. If you confront the worst that could happen you can then look at how you could cope, what you could do and who you could turn to.

Talking

'As a child my mum really helped with my worrying. She would notice when I was quiet and when I couldn't eat because of the butterflies in my stomach and she'd take me to one side. She'd ask me what was wrong, and suddenly facing the worries with someone else really helped. She could help me to see which ones didn't matter and what I could do about others.'

Some people find that talking to someone about their worries really helps. Simply bouncing a worry off another person can help to put it into perspective; you may realise that even the worst possible outcome really isn't the end of the world. Talking about worries can also help when trying to think of a possible course of action to take, as discussion can often throw up solutions or actions that we can't formulate on our own.

You may feel the need to talk about your worries with someone who is not involved in your life. For example you might want to try talking to a counsellor; counselling can help you to gain understanding of your worries and their effects, and it can also support you in doing something about them. Another kind of therapy that can be effective in dealing with worries is cognitive behavioural therapy, which looks practically at the ways in which our thought processes affect our lives, and how we can try to solve the problems they cause by learning to alter destructive patterns of thought.

If you are religious, you might find praying useful in dealing with worries.

Writing worries down

It can help to try writing down all your worries. Some people find it more useful to write their worries as statements rather than questions; so for example 'What will happen if I don't get there on time?' might be more usefully expressed 'I am worried that I won't get there on time.' In this way it is possible to focus on precisely what the fear is.

As we have seen, people often worry about events that are very unlikely to happen. It is often difficult to realise just how unlikely something is when you are preoccupied with it. It might be a good idea to keep your list of worries for a while, before going back to it after a few weeks. You may find that you can cross out some worries, because the event that you were worried about didn't happen or because the worry simply isn't important any more. Of course, you might feel you have a whole new set to replace them with, but if you keep writing them down and then going back to the lists you may see that worries can just 'dissolve'. Some people find that it helps to tear up, burn or otherwise destroy the piece of paper on which they have written their worries. Another constructive way to put worries into perspective is to try to write down the reasons why something bad might *not* happen. This may help you to see more realistically which situations are worthy of worry, and which are not.

How can I
help myself to
stop worrying